

AIDS-Specific Home and Community-Based Waivers for the Medicaid Population

Peter D. Jacobson, Phoebe A. Lindsey,
Anthony H. Pascal

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RAND/UCLA/Harvard
Center for Health Care
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PREFACE

This report was developed for the Health Care Financing Administration (HCFA) as part of RAND's HCFA Center research activities. In this project, RAND was asked to analyze state participation patterns in HCFA's Home and Community-Based Waiver Program for acquired immunodeficiency syndrome (AIDS) patients. The document should be of interest to researchers looking generally at alternative health care services to inpatient care, and to those specifically interested in the provision of health care services to AIDS patients. This work was performed under a cooperative agreement with HCFA and was supported by the RAND/UCLA/Harvard Center for Health Care Financing Policy Research.

SUMMARY

State Medicaid agencies have several organizational options to provide cost-effective health care to the growing numbers of acquired immunodeficiency syndrome (AIDS) patients eligible for Medicaid. This report focuses on the AIDS-specific home and community-based waiver option for AIDS patients, made available in 1985 as an amendment to Section 2176 of the 1981 Omnibus Budget Reconciliation Act. Waivers exempt Medicaid programs from specific statutory and regulatory provisions if such exemptions can be shown to improve cost-effectiveness and delivery of services.

The Health Care Financing Administration (HCFA), the federal agency responsible for administering the 2176 program, has encouraged states to apply for waivers on the grounds that waivers facilitate more cost-effective services to persons with AIDS. States have been slow in applying for AIDS-specific waivers, and the RAND/UCLA/Harvard Center for Health Care Financing Policy Research was asked by HCFA to determine the status of the AIDS waiver among states, to identify reasons why some states chose to apply for an AIDS-specific waiver, and to determine how satisfactory the program was to these states. We were also asked to identify reasons why other states with a substantial number of AIDS patients were not applying for AIDS waivers.

This report begins with an overview of the home and community-based waiver program's purpose, the types of waivers for which states may apply, and the waiver application, reporting, and renewal processes. Section 2176 permits states to offer, under a waiver, an array of home and community-based services as an alternative to institutionalization in appropriate cases. Services such as homemaker, home health aide, and personal care are provided in the patient's home. Other services—including case management, adult day care, and respite care—are provided by a community agency, typically in a community setting. The "other" category, particularly as it applies to AIDS waivers, offers considerable flexibility in designing a broad range of services applicable to the AIDS population.

Although there is no application form as such, states must specify the scope of the waivers requested, describe the waiver participants, define the services, address safeguards and evaluations, describe the plan of care, provide freedom of choice assurances and documentation, and provide assurances and documentation for the cost-effectiveness of the waiver. By statute, the waiver services' costs must be budget-neutral, and HCFA provides a complex formula by which such

determinations must be specified. An annual report on the program must be submitted to HCFA assuring that the health and welfare of patients has been assessed, and comparing cost projections to actual costs incurred.

We present a review of the literature on this topic and identify related research efforts under way that will eventually add to our understanding of how Medicaid programs serve AIDS patients. The dominant conclusion that emerges from this literature is that home and community-based programs have not proved cost-effective for the aged and disabled waiver populations. The reasons for the conclusion vary according to the program studied, but the primary problem seems to be the inability of programs to develop effective screening mechanisms to identify persons at risk for institutional care. Unless services are targeted to patients who would otherwise use institutional services, home and community-based care acts as a complement rather than a substitute for nursing home care. Earlier waiver demonstration projects were designed to divert patients from nursing homes to community-based care. With AIDS patients, the 2176 waiver program substitutes home and community-based care for hospital care. Because hospital care is much more expensive per day than nursing home care, the necessary reduction in inpatient length of stay for AIDS patients must be comparatively smaller to justify the waiver program's costs.

We then describe the experience of current waiver states. As of January 1, 1989, six states had operational AIDS waivers: California, Hawaii, New Mexico, New Jersey, Ohio, and South Carolina—with New Jersey's waiver in operation since March 1987, and California's the most recently implemented, in January 1989. These states pursued the waiver because of a concern about the projected number of AIDS patients they might expect to serve in future years and about the suitability of services they could provide without the flexibility of a waiver. Further, states with relatively high federal participation match rates saw the waiver as an opportunity to secure additional program dollars for an emerging health crisis.

The number of services provided by each state ranges from 13 in Hawaii to 5 in New Mexico. Five of the six states cover case management, personal care, and adult day care as part of their waiver services; four programs provide some additional services for human immunodeficiency virus-(HIV-)infected foster children and/or their parents.

States with operational waivers indicate that the AIDS-specific waiver enables them to:

- Establish a uniform system of services;
- Establish an AIDS treatment network;

- Identify and rectify gaps in service delivery;
- Provide greater access to home and community-based care for AIDS patients;
- Provide new services, such as foster group homes, for infected children;
- Provide flexibility in service design and delivery;
- Expand financial eligibility for AIDS patients.

The degree of flexibility inherent in the 2176 waiver process is a subject of debate among states: States with waivers say they obtained greater flexibility, while states that have not applied for a waiver view the program as being inflexible. The application and reporting processes can be complex, and implementing and monitoring a waiver program clearly absorbs considerable administrative resources.

Five states are currently in the process of applying to HCFA for an AIDS-specific waiver—Connecticut, Florida, Georgia, Pennsylvania, and Texas. Other states with a high number of AIDS cases—New York, for example—have not applied for a waiver. We sampled several states—including Illinois, Massachusetts, Michigan, the District of Columbia, Maryland, and New York—with AIDS populations that would suggest the waiver might be an appropriate mechanism for providing additional Medicaid services, but that had not applied for an AIDS-specific waiver.

We wanted to determine if a waiver application was under consideration, and if not, why not. Two consistent complaints were the states' concerns about the application process and about the administrative burdens that would be added to their agencies. A key element of this concern was the cost-effectiveness formula, judged by many as cumbersome and misdirected. Many of these states were using other programmatic approaches to provide services to persons with AIDS, including expanding Medicaid's optional services, adding a case management capability, or using a model waiver.

We conclude with a description of our recommendations for the program and for future research. Although the states that have implemented such waivers intend to retain—and in some cases expand—this capability, our research suggests that several ways exist to make this program even more palatable and attractive to Medicaid agencies, including:

- Easing the administration and reporting requirements of the waiver;
- Considering increasing the program's flexibility, especially regarding eligibility and the range of programs allowable; this would encourage state innovation;

- Relaxing the requirements that cost savings be demonstrated before a waiver can be granted; focusing as much on the efficiency and quality of service delivery to program clients as on budget neutrality;
- Simplifying the cost-effectiveness formula;
- Reducing the waiver application's processing time;
- Encouraging states that have waivers in place to perform ongoing evaluations and provide forums where these observations can be shared with states without waivers;
- Developing a preadmission screening instrument that enables a state to identify AIDS patients in the community who would otherwise need institutional care;
- Developing standard data collection methodologies for all waiver states;
- Improving the program's marketing to stress flexibility in service delivery and expanded eligibility;
- Providing a definition of what services can be offered under the "other services" category of the regulations;
- Developing strategies to encourage private care providers to provide care to AIDS patients;
- Developing strategies to consider providing housing and nonmedical services under the waiver program.

Areas in which additional research is needed include program implementation, adequacy of service delivery, cost-effectiveness, and the quality of care under waiver programs. We also identify data sources and data needs.

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We received valuable support throughout this project from Dave Baugh and Penny Pine of the Health Care Financing Administration (HCFA). Bob Wardwell and Sue Davison of HCFA also provided valuable information. We also appreciate the time spent by various state officials in describing their waiver programs to us. In particular, Carol Kurland of New Jersey and James Waltner of New Mexico deserve special attention. We appreciate the thoughtful reviews of an earlier draft by RAND colleagues Geri Dallek and Anne Johansen. Finally, RAND colleagues Charles Bennett and Marilyn Cvitanic provided useful information and suggestions.

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I. INTRODUCTION

Acquired immunodeficiency syndrome (AIDS) is a deadly disease with an unusually long incubation period (a median of perhaps eight years, based on current knowledge) that is affecting an increasing number of persons in the United States. No longer limited to the homosexual and bisexual populations, AIDS is increasingly manifest in the heterosexual population and affects children born to AIDS-infected mothers as well. The disease's incapacitating nature and the associated high medical and therapeutic costs can quickly decimate an individual's resources, forcing him or her to look to Medicaid as the payer of last resort for health care.¹ State Medicaid agencies, challenged to provide adequate health care services to a new, growing, and costly population of users, are faced with two opposing tensions in allocating their resources. First, agencies face resource cutbacks and limitations at both the state and the federal levels. Second, Medicaid agencies have been simultaneously directed by the various Omnibus Budget Reconciliation Acts (OBRA's) to expand eligibility (and thus expenditures) for services, especially for mothers and children.

Medicaid agencies have several alternatives under which they may organize health care services for AIDS patients. These include providing:

- Inpatient, outpatient, and other Medicaid services on a traditional basis;
- A wide range of additional optional services that meet many patients' needs;
- Home and community-based services for the disabled (or other designated populations) under a 2176 waiver;
- Special services to an individual or a small group of like individuals under a model 2176 waiver; and/or
- Noninstitutional services to the AIDS patient under an AIDS-specific 2176 waiver.

OBRA 1981 gave the Health Care Financing Administration (HCFA), the U.S. Department of Health and Human Services (DHHS) agency responsible for administering the federal-state Medicaid program, the authority to waive certain Medicaid statutory and regulatory

¹Persons with a diagnosis of AIDS are presumptively disabled and thus are categorically eligible for Medicaid. Special income provisions are established in some states to expand Medicaid eligibility for AIDS patients.

provisions for applicant states if alternative services could be offered on a cost-effective basis without impairing access to high-quality services. Section 2176 of OBRA 1981 specifically permits the provision of home and community-based services as an alternative to more costly institutional services.

AIDS-specific home and community-based waivers have provided an option to increase access to Medicaid services for AIDS patients since they were authorized in OBRA 1985. HCFA has encouraged states to apply for AIDS-specific 2176 waivers, but states have been slow in applying. At the end of January 1989, only six states had HCFA-approved AIDS waivers.

STUDY DESIGN AND METHODOLOGY

To complement earlier work on AIDS policy, HCFA asked the RAND/UCLA/Harvard Center for Health Care Financing Policy Research to determine the status of the AIDS waiver among states, to identify reasons why some states chose to apply for an AIDS-specific waiver, and to determine how satisfactory the program was to those states. We were also asked to identify reasons why other states with a substantial number of AIDS patients were not applying for a waiver. Finally, we were asked to provide recommendations for assessing the program and suggestions for future research and data needs.

The study design consisted of identifying and selecting representative states for in-depth telephone or in-person interviews. Before contacting the states, we met with HCFA officials to identify the status of AIDS-waiver applications, review the application and annual reporting processes, and review selected state waiver applications.

We contacted all the states (New Jersey, New Mexico, Ohio, Hawaii, South Carolina, and California) with operational waivers to discuss their experiences. In addition, we identified a sample of states to ask about their understanding of the waiver program and their intentions regarding a waiver application. In all, we contacted 13 states: Illinois, Texas, Georgia, Pennsylvania, Florida, New York, Massachusetts, Michigan, the District of Columbia, Maryland, Connecticut, Utah, and South Dakota. We chose these states because each has more than 1000 diagnosed AIDS cases and/or more than a \$1.00 per capita expenditure for AIDS (Rowe and Ryan, 1988). We selected states to include some with significant AIDS populations (New York and Florida), some with relatively high federal participation rates (Georgia), and some with a more limited number of optional Medicaid services (Texas and Pennsylvania). Thus, we would expect these states to be representa-

tive of those that might be candidates for the AIDS-specific 2176 program. Utah and South Dakota were chosen as states with a low number of reported AIDS cases to provide comparative information on states unlikely to be candidates for the 2176 program.

During the interviews, we asked program representatives a series of questions covering the following topics: waiver program assessment, including expected cost savings; reasons for waiver application/reasons for not applying; services provided to AIDS patients under Medicaid; data availability; proposed program expansion; proposed research questions; and recommendations for HCFA program administration.

ORGANIZATION OF THE REPORT

This report begins with a description of the home and community-based waiver program's purpose, the types of waivers for which states may apply, and the waiver application, reporting, and renewal processes. Next, we present a review of the literature on this topic and identify related research efforts under way that will eventually add to our understanding of how Medicaid programs serve AIDS patients. We then review the current status of AIDS-specific waivers, focusing on the experience of states with operational AIDS waivers. We describe the results of our discussions with non-AIDS waiver states on the reasons for not seeking such a waiver. The report's next section identifies future research topics as well as the data available and/or needed to address a research agenda for improving Medicaid services to AIDS patients. Finally, we report our recommendations for program changes.

II. HOME AND COMMUNITY-BASED WAIVERS

PURPOSE AND STRUCTURE

Because of concerns with the rising costs of the Medicaid program, a large portion of which were attributed to the increasing costs of institutional care, Congress included Section 2176 in OBRA 1981 (Section 1915[c] of the Social Security Act). This section permits states to offer, under a waiver, an array of home and community-based services as an alternative to institutionalization in appropriate cases (see Table 1). Services such as homemaker, home health aide, and personal care are provided in the patient's home to enable the patient to remain in his or her home setting. Other services—including case management, adult day care, and respite care—are provided by a community agency in a community setting to a number of patients to deter institutionalization.

Four eligibility groups—aged, disabled, mentally retarded, and mentally ill—were specified under the original law. AIDS patients were added by OBRA 1985. In 1988, Section 1915(e) was added to the Social Security Act; it permitted waiver services to drug-dependent children and children infected with AIDS.

Federal financial incentives encourage state applications for all 2176 waivers, including the AIDS-specific waiver, particularly for states with high federal financial participation rates. An important programmatic advantage to the waiver is that specific Medicaid services can be targeted to patients and limited to particular geographic areas rather than being delivered statewide. The waiver program exempts the state from the standard Medicaid provisions of offering comparable services on a statewide basis to Medicaid-eligibles.

Ten basic service categories can be provided as home and community-based services: case management, homemaker, home health aide, personal care, adult day care, habilitation, respite care, day treatment or other partial hospitalization services, psychosocial rehabilitation and clinic services (whether or not furnished in a facility for individuals with chronic mental illness), and other services. The "other" category, particularly as it applies to AIDS waivers, offers considerable flexibility in designing a broad range of services necessary to this particular population (see Table 1). All but one state has applied for waivers to serve one or more of the six eligibility groups, and only four states do not as yet have any type of waiver program (not all state applications have been approved). As of January 1, 1989, six states had operational AIDS waivers.

Table 1
HOME AND COMMUNITY-BASED WAIVERS: OPTIONS

Case management
Homemaker
Home health aide
Personal care
Adult day care
Habilitation
Day treatment and other partial hospitalization, and other services for the chronically mentally ill
Respite care
Psychosocial rehabilitation and clinic services
Other (composite list from state waiver applications)
Adaptive/assistive equipment
Attendant care
Counseling/training
Nutritional
Psychological
Emergency alarm response system
Home delivered meals
Medical supplies
Minor home adaptations
Moving assistance
Narcotic and drug abuse treatment
Private-duty nursing
Screening/assessment
Skilled nursing facility
Supervision/supplement for infants and children in foster care
Transportation

An additional type of 2176 waiver, the model waiver, was instituted in 1982 as a result of the "Katie Beckett" case. Katie was a ventilator-dependent child whose parents preferred to care for her at home, but whose deinstitutionalization would have resulted in the loss of her Supplemental Security income (SSI) and Medicaid eligibility. Before the Beckett case, DHHS waived the requirement for institutionalization as essential to Medicaid eligibility on a case-by-case basis. In the meantime, the states were pursuing options for addressing the problem of individuals whose home-provided care would be less costly and of equal quality to institutional care. DHHS introduced the model waiver concept to allow states to "batch" these individual requests, including as many as 200 individuals with the same condition under a

model waiver.¹ At least two states, Illinois and North Carolina, are currently using the model waiver to provide services to individuals with AIDS.

PLANNING FOR AIDS SERVICES

Because AIDS is such a recently identified disease and is highly virulent, and because our understanding of effective interventions is still limited, developing a waiver application and planning for AIDS services generally are fraught with more than the usual uncertainties. Planners do not know, for example, how close we are to having a vaccine, how much our testing and diagnostic skills might improve, what promises drug research holds for amelioration or prospective cure, what additional surprises await in terms of transmission, whether our understanding of the period of incubation will change, what behavior changes we might expect from health education efforts, and what specific services will be needed and how exactly to provide them. An added problem is how to address this disease's stigma—namely, discrimination against AIDS victims and the unwillingness of certain providers (such as nursing homes) to admit AIDS patients. Planning for the needs of a stigmatized population must also occur in the political environment of each state's resources and commitment to social services programs for its residents.

THE WAIVER APPLICATION, APPROVAL, AND RENEWAL PROCESSES

Table 2 charts the waiver application process. Medicaid agencies interested in alternatives to institutionalization for AIDS patients may apply to HCFA's Bureau of Eligibility, Reimbursement, and Coverage (BERC) for a 2176 waiver. Although there is no application form as such, applicants must specify the scope of the waivers requested, describe the waiver participants, define the services, address safeguards and evaluations, describe the plan of care, provide freedom of choice assurances and documentation, and provide assurances and documentation for the waiver's cost-effectiveness. Provision of services at the home and community level cannot exceed the dollar costs of institutionalizing the target population. By statute, the costs of the waiver services must be budget-neutral—that is, the total costs of providing

¹Originally the number of similar cases that could be batched was 50, but this was increased to 200 in April 1986.

Table 2

THE HOME AND COMMUNITY-BASED (2176) WAIVER PROCESS

Document	HCFA Recipient Agency	Possible HCFA Actions
Waiver application	BERC: Has 90 days to act, once application deemed complete	1) Approve for three years 2) Disapprove 3) (a)
372 annual report	BQC: Due six months after completion of first year of operation under the waiver	BQC sends part IX-D to BERC for its action BQC determines and advises BERC whether waiver is cost-effective
Renewal applications	BERC: Regional office site visits state Takes into account BQC comments on cost-effectiveness	1) Approve for five years 2) Disapprove 3) (a)

NOTES: HCFA = Health Care Financing Administration; BERC = Bureau of Eligibility, Reimbursement, and Coverage; BQC = Bureau of Quality Control.

^aStates can withdraw application.

Medicaid services for AIDS patients under the waiver must not exceed what they would have cost without a waiver. HCFA provides a complex formula by which such determinations must be specified.² The cost-effectiveness formula, structured to compare total Medicaid costs with and without the waiver, follows:

$$\frac{(A \times B) + (A' \times B') + (C \times D) + (C' \times D') + (H \times I)}{F + H} - \frac{(F \times G) + (H \times I) + (F' \times G')}{F + H}$$

where A = estimated number of beneficiaries who would receive the level of care provided in a skilled nursing facility (SNF), intermediate care facility (ICF), or intermediate care facility for the mentally retarded (ICR/MR) with the waiver;

B = estimated annual Medicaid expenditure for SNF, ICF, or ICF/MR care per eligible Medicaid user with the waiver;

C = estimated number of beneficiaries who would receive home and community-based services under the waiver;

²U.S. Department of Health and Human Services, *State Medicaid Manual*, Part 4, "Services," September 1988.

D = estimated annual Medicaid expenditure for home and community-based services per eligible Medicaid user;

F = estimated number of beneficiaries who would likely receive the level of care provided in an SNF, ICF, or ICF/MR in the absence of the waiver;

G = estimated annual Medicaid expenditure for SNF, ICF, or ICF/MR care per eligible Medicaid user in the absence of the waiver;

H = estimated number of beneficiaries who would receive any of the noninstitutional, long-term care services otherwise provided under the state plan as an alternative to institutional care;

I = estimated Medicaid payment per eligible Medicaid user of the noninstitutional services referred to in H;

A' = estimated annual number of beneficiaries referred to in A who would receive any of the acute care services otherwise provided under the state plan;

B' = estimated annual Medicaid expenditure per Medicaid eligible user of the acute care services referred to in A';

C' = estimated number of beneficiaries referred to in C who would receive any of the acute care services otherwise provided under the state plan;

D' = estimated annual Medicaid expenditure per eligible Medicaid user of the acute care services referred to in C';

F' = estimated annual number of beneficiaries referred to in F who would receive any of the acute care services otherwise provided under the state plan;

G' = estimated annual Medicaid expenditure per eligible Medicaid user of the acute care services referred to in F.

Once BERC has declared an application complete, it has 90 days in which either to approve the waiver for a three-year period or disapprove the waiver. The state has the option of withdrawing its application at any time during this 90-day period.

States must fulfill regular waiver reporting requirements for HCFA. They must submit an annual report on the home and community-based services waiver (form HCFA-372) to the Bureau of Quality Control (BQC) within six months after the close of the first full year of operation (see App. A). A narrative section assuring that the health and welfare of waiver patients has been assessed and that problems, if discovered, have been addressed, is carefully reviewed by BERC. The

waiver's financial report section is scrutinized by BQC.³ Data are compared with the projections made in the waiver application and with the 2082 form, an annual report of Medicaid payments submitted by each Medicaid agency to HCFA's actuary. Major discrepancies are discussed with the Medicaid agency and revisions and corrections may be required by BQC.

Pending approval by the Executive Office of Management and Budget, HCFA is altering form 372 in an effort to collect only those data items they consistently use and that can be computerized. HCFA has proposed eliminating a series of questions from Sec. IX, data not specifically related to formula factor values—values Medicaid agencies have indicated are difficult to address.

Renewal applications are made to BERC. Form 372 is an essential part of the renewal process, and the waiver's cost-effectiveness (based on the above formula) is given particular attention. As part of the renewal process, the appropriate DHHS regional office conducts a program review (which may involve a site visit) and submits a target area report to both the state agency and HCFA. The TARS report assesses the Medicaid agency's implementation and operation of the waiver program, whether health and safety considerations are being appropriately addressed, and how the program's cost-effectiveness is being evaluated. At the end of the three-year period, BERC has two options: to renew the waiver for a period of five years, or to disapprove the waiver. State agencies may also withdraw their requests for waiver renewals during this review process.

³Because form 372 is not due until 18 months after the waiver's initiation date and because extensions on due dates are possible, no form 372s were available for our review, even though the first AIDS waiver was instituted in March 1987.

III. LITERATURE REVIEW

METHODOLOGY

The literature on the Medicaid Home and Community-Based Waiver Program is not very extensive; most of it has resulted from HCFA evaluation contracts. For the AIDS-specific waiver program, virtually no literature is available (as might be expected given the program's short history). In contrast, a substantial body of literature exists on managed care, community-based care (for nonwaiver populations), and general AIDS issues (primarily cost estimates). Although managed care is just one aspect of home and community-based care, managed care has been the predominant component of previous demonstration projects. In this review, we will summarize the available literature to draw conclusions that might pertain to the AIDS waiver program.

Our purpose in reviewing the literature is fourfold. First, we want to identify the attributes of previous waiver demonstration projects that will be applicable to the AIDS waiver program. Second, we want to compare the specific waiver literature with the more general managed care literature. Next, we want to identify how AIDS patients might differ from other chronically ill populations served under other waiver programs. Finally, we want to identify the range of research questions left unanswered in the current available literature.

The bibliography suggests the scope of our literature review. We have reviewed most of the reported literature, including evaluation reports prepared for HCFA. Although we have not attempted a full-scale methodological critique of each study, we do discuss some methodological problems that might limit our ability to generalize from the studies we reviewed.

LITERATURE ON THE WAIVER PROGRAM

National Evaluation of the 2176 Waiver Program

We look first at evaluations of the Medicaid 2176 waiver program as originally enacted in 1981. Most of the literature has resulted from HCFA-sponsored evaluations. We will not review the early reports, which primarily studied the legislative history or reviewed the types of services provided through state waivers (see Gardner, 1986).

The most extensive work on the 2176 program has been the national evaluation conducted by the La Jolla Management Corporation (Clinkscale, 1988a; Clinkscale, 1988b; Vertrees and Clinkscale, 1988; Burwell, 1988; Laudicina and Burwell, 1988; Clinkscale and Ray, 1987). Using 1985 and 1986 data to review six waiver programs (including four case studies), the summary report (Clinkscale, 1988b) evaluated both the cost-effectiveness and quality of waiver programs. The study's most important conclusion was that the waiver program made no "statistical difference on overall national trends for Medicaid-funded nursing home and ICF/MR [intermediate care facilities for the mentally retarded] use and expenditures." Somewhat inconsistently, the study found that there were indeed reported cost savings from the waiver programs (although the authors discount this result because of unreliable data reporting to HCFA).¹

The Clinkscale report also concluded that sufficient targeting accuracy to maintain budget neutrality is doubtful. No evidence was found to show that the waivers reduced program spending rates, and no statistically significant differences in expenditures existed between waiver and nonwaiver states. According to the authors, the most likely explanation was that existing preadmission screening to identify patients who would otherwise need institutional care was not sufficiently accurate to guarantee program savings. Thus, the study concluded that accurate mandatory preadmission screening was necessary for generating cost savings.

Another important conclusion reached by the La Jolla evaluation was that each program needed to be evaluated separately, especially with regard to quality of care. For example, Clinkscale (1988b) states that quality assurance in waiver programs was likely to be very good, but that institutional quality of care for certain waiver populations—especially ICF/MR patients—was likely to be better than community-based care. Thus, evaluations of the AIDS waiver should account for quality as well as cost savings.

Results from this study are not necessarily generalizable to the AIDS waiver program, although the results are consistent with other studies. As Vertrees and Clinkscale (1988) point out, the study's limitations include small numbers of waiver recipients in proportion to the total Medicaid population, low penetration rates of waiver programs, and the

¹According to the Government Accounting Office (GAO; 1987), data collected on the 372 forms for the home and community-based waiver program during its first five years are generally not accurate or useful for evaluations. To the extent that program evaluations (such as the Clinkscale study) rely on these data, conclusions generated must be tentative. As we will discuss later, we share GAO's concerns about the underlying assumptions used to determine cost savings based on the 372 forms.

demand for nursing home beds relative to supply. If a waiting list exists for nursing home beds, a person diverted from long-term care because of waiver services will simply be replaced by someone on the waiting list. When this occurs, discerning any cost savings from the waiver program is difficult (Laudicina and Burwell, 1988). Because AIDS patients are more likely to be diverted from hospitals than from nursing homes, cost savings may be easier to determine.

Other 2176 Evaluations

Although each state is required to conduct an independent assessment of its waiver program, the published literature reporting such evaluations is sparse. However, a recent evaluation of the Connecticut waiver program by Yeatts, Capitman, and Steinhardt (1987) essentially supports the La Jolla findings.

The Connecticut waiver is limited to Medicaid-eligible elderly patients being discharged from the hospital, in the belief that these persons are most likely to enter a nursing home but for the waiver services. Patients expected to be discharged to nursing homes were given a preadmission screening to determine the appropriate level of care. For patients meeting the skilled nursing facility (SNF)-ICF care levels, a further assessment was made to determine if they could instead be served in the community.

The authors concluded that showing what percentage of patients at risk of nursing home care actually would have entered a nursing home but for waiver services was not possible. Thus, the authors could not calculate accurately any reductions in Medicaid expenditures. This study's basic limitation is that the authors base their conclusion on other studies (such as Blackman, Brown, and Learner, 1985), which showed that only a certain percentage of persons at risk actually entered a nursing home. As a result, the study is not as useful as it might have been.

LITERATURE ON MANAGED CARE

The Channeling Demonstration

In 1988, the final results of the channeling demonstration project (formally the National Long-Term Care Demonstration) were issued.² Basically, this demonstration attempted to ascertain whether extensive

²The entire evaluation is reported in *Health Services Research*, Vol. 23, No. 1, 1988 (cited here as Kemper et al., 1988).

case management would result in the substitution of community care for long-term nursing home care and reduce costs. The program evaluation found that the desired effects did not occur, which is consistent with the La Jolla findings for the 2176 program.

The channeling demonstration was designed to serve severely impaired older persons at high risk of institutional placement in a nursing home and to substitute community services for such placement. The design specified two models: a basic case management design and a financial control model. Both encompassed so-called core features of case management (such as outreach, screening, eligibility, assessment, and placement), and both relied on people who applied voluntarily to the channeling projects (raising selection issues). Within each model, eligible participants were randomly assigned to a treatment or control group.

The demonstration found no large substitution of community services for institutional care. As a result, case management services were an add-on to institutional care, hence increasing costs. Of equal importance, the demonstration suggested little improvement in functional status. The study suggested, however, that channeling did increase clients' satisfaction with life (Kemper et al., 1988).

One point to keep in mind is that the channeling demonstration models measured effects relative to existing community service levels. Thus, some of the population (an estimated 10-20 percent) were already receiving comprehensive community services and case management equivalent to the basic model. In short, this was not a test of case management relative to no case management. In addition, several methodological challenges can be raised about the project's underlying design, especially the use of narrow targeting criteria for patients at risk of institutional care (ironically leading to a participant population at lower risk of institutional care), excessive caps on treatment costs (undermining incentives to reduce case expenditures), and selection bias.

These and other methodological problems suggested by the authors cannot entirely obscure the demonstration's results—that case management does not save costs as a substitute for nursing home care.

Other Section 1115 Medicaid Waiver Demonstration Projects

Before the current 2176 program, HCFA sponsored a waiver demonstration program under Section 1115 of the Social Security Act's Title XIX. By consensus, the most successful 1115 Medicaid long-term care waiver program was the South Carolina Community Long-Term Care Project, which served individuals requesting nursing home care

(Blackman, Brown, and Learner, 1985). Like the Connecticut program described above, the South Carolina project relied on a preadmission screen for Medicaid-eligible nursing home applicants to identify those at risk of institutionalization. The target population, disabled adults eligible for Medicaid-funded nursing care, was divided into two groups: a control group that received nursing home services, and an experimental group that was provided with a range of community-based services arranged through extensive case management (Blackman, Brown, and Learner, 1985; Nocks et al., 1986).

In the subsequent program evaluation, Nocks et al. (1986) found that the experimental group used statistically significant fewer nursing home services than did the control group over an 18-month period. Most important, the reduction in nursing home use did not result in any "observed negative effects on measures of functional health status, mental health status, or mortality."

This project demonstrates that the ability to identify persons at risk for institutionalization, coupled with an effective community-based service system, is the key to a successful program. Earlier 1115 programs, such as the Wisconsin Community Care Organization, were unable to target clients who would have been served in a nursing home but for the community-based care, and hence showed no reduction in nursing home use as a result of community services (Applebaum, Seidl, and Austin, 1980; see also Capitman, 1986; Skellie and Coan, 1980; Skellie, Mobley, and Coan, 1982; and Birnbaum et al., 1984).

AIDS LITERATURE

Most AIDS literature deals with disease epidemiology and costs rather than service delivery (Benjamin, 1989; Scitovsky, Cline, and Lee, 1986; Seage et al., 1986; Pascal, 1987; Andrulis et al., 1987). In looking at service delivery, much of the attention has focused on San Francisco (Arno, 1986), a nonrepresentative environment with extensive volunteer services. In contrast to reports of national costs for treating AIDS patients (Scitovsky and Rice, 1987; Sisk, 1987), it appears that treatment costs are lower in San Francisco, largely as a result of considerable volunteer labor pools (Arno, 1986; Arno and Hughes, 1987; Scitovsky, Cline, and Lee, 1986).

Although local variations in case mix and practice patterns may account for some of the cost differential, the availability of volunteer labor does permit earlier hospital discharge than in other areas (Arno and Hughes, 1987; Scitovsky, Cline, and Lee, 1986). Thus, an important issue is the availability of volunteer labor in other communities

and the desirability of using this model. As discussed below, how the volunteer labor is valued is an important aspect of whether community-based services can reduce costs for AIDS patients. This suggests that much more research on service delivery for AIDS patients is needed. We will return to this subject below.

Given the substantial inpatient costs incurred for treating AIDS, the opportunity for cost reduction through home and community-based services is potentially significant. This effect will be reinforced if hospital costs for treating AIDS patients are greater than costs for treating non-AIDS patients (see Andrews, Keyes, and Pine, 1988). As Benjamin (1989) points out, however, many factors—such as length of stay (LOS) variation across communities (for reasons other than community-care substitutes), or changes in disease management—may limit the eventual savings potential.

ANALYSIS OF THE LITERATURE

The dominant conclusion that emerges from this literature review is that home and community-based programs have not saved costs so far. With two important exceptions—programs in South Carolina and San Francisco—the literature is consistent on this point. No one suggests that community-based care is not an important component of a health care delivery system, just that it is not likely to generate significant cost savings.

However, three important limitations to this general conclusion should be considered. First, the previous studies have methodological limitations. Second, some programs have shown cost savings, largely as a result of better targeting and intervention strategies (Blackman, Brown, and Learner, 1985; Weissert, Cready, and Pawelak, 1988). Third, the previous demonstration projects were designed to divert patients from nursing homes to community-based care. With AIDS patients, the 2176 waiver program substitutes home and community-based care for hospital care.

Methodological Limitations

The methodological limitations in the existing managed care literature include selection bias (that is, the failure to compare equivalent groups), the failure to measure patient outcomes, and the failure to conduct cost-effectiveness studies.

Selection bias is an important limitation in the available studies. As Nocks et al. (1986) point out, comparisons must be between equivalent

groups—if possible, through a randomized controlled trial. Ideally, there would be identical sets of people, all of whom are known to be predisposed toward the use of nursing home services in the absence of Medicaid waivers that subsidize these services. Nocks et al. add that community-based programs may expand the user base, thus serving persons who would otherwise not receive nursing home care under current conditions.

A similar concern was raised by Weissert, Cready, and Pawelak (1988), who criticized previous studies for failing to identify subgroups of patients with different needs. By treating each patient as equally likely to benefit from all aspects of care, these studies are unable to distinguish which groups are more likely to benefit from home and community-based care. Serving certain subgroups in the community is more cost-effective than serving others, so that results generated for one subgroup may not be applicable to others. With the emergence of pediatric AIDS patients as a public policy concern, the subgroup analysis in the AIDS waiver program may become increasingly important.

None of the reported studies attempt to adjust for patient outcomes or to measure how effective these services are relative to institutional care. By focusing on the narrower cost savings issues, previous evaluations may underestimate the service benefits of the waiver program on quality of life (see, for example, Birnbaum et al., 1984). As such, the literature often ignores the basic goal of any program, which is to deliver services needed by the population at risk. If those services can be delivered in a cost-effective way, even without cost savings, then the program needs to be evaluated further based on the benefits it provides. Client and family satisfaction are thus important issues to consider.

In other words, a cost-effectiveness (or cost-benefit) analysis focusing on clinical benefits (adjusting for patient outcomes) of waiver services is necessary. If the program goal is budget neutrality, the only way to evaluate the program is through quality of care. If, however, the program goal is cost savings, then the evaluation needs to hold quality of care constant.

Cost Savings of Community-Based Care

One of the primary reasons for the difficulty in showing cost savings is the inability to develop effective prescreening instruments to identify who might be at risk of institutional placement (Yeatts, Capitman, and Steinhardt, 1987; Long and Settle, 1988; Weissert, 1985; Weissert, Cready, and Pawelak, 1988; Laudicina and Burwell, 1988). In con-

trolled studies, for instance, control groups have low nursing home utilization rates, suggesting limitations to reducing nursing home costs (Weissert, Cready, and Pawelak, 1988). Generating program savings depends on substituting waiver services for institutional care. In turn, this substitution depends on whether patients would have actually used institutional services but for the availability of the waiver program (Laudicina and Burwell, 1988). Unless services are targeted to patients who would otherwise use institutional services, home and community-based care acts as a complement rather than a substitute for nursing home care (Weissert, Cready, and Pawelak, 1988; Moscovice, Davidson, and McCaffrey, 1988).

Another reason for the limited cost savings of home and community-based programs to date is that a good deal of cost shifting to other federal programs may occur, negating savings from increased community-based care (Clinkscale, 1988b). To the extent that waiver programs create an incentive to shift service delivery costs from other state-funded programs, Medicaid pays a portion of that shift. A potential for increased federal cost sharing from Medicare, SSI, food stamps, and housing subsidies may also exist.

The existence of nursing home waiting lists is a further obstacle to reducing Medicaid nursing home expenditures. Because of the waiting list, nursing home costs are not reduced by providing waiver services, but the added cost of waiver services is incurred by the Medicaid program (Yeatts, Capitman, and Steinhardt, 1987; Laudicina and Burwell, 1988). (A similar finding regarding expanded home health care benefits was made by the General Accounting Office [GAO] in 1983).

These observations may not be as important for AIDS patients because most institutional care will be in a hospital rather than in a nursing home. In San Francisco, for example, Arno (1986) found that home and community-based care for AIDS patients was cost-effective, given a large supply of volunteer labor. Interestingly, Weissert, Cready, and Pawelak (1988) concluded that home and community-based services were more likely to prove cost-effective for terminal patients because of the limited time during which treatment costs would be incurred.

Furthermore, the 2176 waiver program involves more services than just case management, as Table 1 shows. To the extent that utilizing services beyond case management makes program delivery more efficient, the conclusions about cost savings, discussed above, may not be directly applicable.

Applying the Literature to the AIDS Waiver

An important question, therefore, is whether waiver programs for the AIDS population are more likely to resemble the few studies showing cost savings or the more numerous studies showing no savings. Are the purposes of the AIDS waiver different from the other waiver programs? Or do certain differences exist in the AIDS population that suggest the waiver program may indeed be cost-effective? Because hospital care is much more expensive per day than nursing home care (for example, \$825 versus \$115 [Pascal, 1987]), the necessary reduction in inpatient LOS must be comparatively smaller for AIDS patients to justify the waiver program's costs. At present, few nursing homes seem willing to admit AIDS patients. Thus, there may be little long-term care to be avoided with AIDS patients in any event. And because the probability of hospital use by AIDS patients is greater than the probability of nursing home use by the elderly (Benjamin, 1989), the opportunities for cost savings may be greater with AIDS patients.

One of the most important articles (Weissert, 1985) challenging the cost-effectiveness of home and community-based care for the elderly raises seven reasons why home and community-based programs for the sick elderly do not reduce institutional care. Are these seven reasons equally applicable to the AIDS waiver program? In the following discussion, we list each of Weissert's concerns, followed by a brief assessment of the applicability to AIDS patients.

1. *Most patients using home and community-based care do so as an add-on to existing care rather than as a substitute for institutional care.* Because the disease progression of AIDS is different from diseases afflicting the frail elderly—in particular, the sporadic need for inpatient care—there is an opportunity for home and community-based care to reduce the need for hospital inpatient care. This may be particularly true at the end-of-life stage. In addition, AIDS patients may not be similar to other chronically ill patients.

2. *Most community care users at risk of institutionalization (that is, nursing home care), are at risk for only a short time.* AIDS patients are also in and out of hospitals with relatively short inpatient episodes. Although the lifetime inpatient days may not be significant, some hospitalization is probably unavoidable. Indeed, to the extent that AZT and similar pharmaceuticals extend patient survival times, these short acute care episodes may even increase in number over a lifetime. Nevertheless, some episodes may be effectively treated in the community, and the duration of others may be reduced by the availability of community care both before and after an inpatient episode. Even so, data from the National Channeling Demonstration suggest that, at

least for the elderly, community care made no difference in hospital admission rates or in LOS, adjusting for case mix.

3. *The magnitude of community care's effect on institutionalization rates has been small; hence, expected savings are too small to offset community care costs.* As noted above, because hospital care is much more expensive per day than nursing home care, the needed reduction in inpatient LOS must be comparatively smaller for AIDS patients to justify the waiver program's costs. Without better data on admission rates and LOS, determining at this time how extensive the savings might be for AIDS patients is impossible. This question will likely be important in future research.

4. *Patients at high risk of institutionalization are very difficult to find in the community.* Throughout the case management and channeling literature, we see that precise targeting of people in the community who are at risk of future institutionalization is essential to the success of community-based care. Unless the people who would otherwise be institutionalized but for the waiver can be identified, no way to reduce the institutional costs exists. In the South Carolina waiver program, for example, administrators were able to devise an effective screen; hence, the waiver program reduced costs. Other programs have been unable to do so, and thus have not succeeded.

For AIDS patients, the issue will be identifying which services are most effective in limiting inpatient admissions or LOS by identifying patients prior to admission. Once diagnosed as having AIDS, the patient will clearly need some hospital care; thus, a waiver program may operate to reduce somewhat the lifetime institutional costs.

5. *The combination of the low prevalence of high-risk clients and high demand for community care among patients not at high risk forces community care programs to screen applicants carefully and periodically reassess their continued high-risk status.* For AIDS patients, this added administrative cost should not be a factor. Once a patient is diagnosed as having AIDS, all doubts about risk are removed. Therefore, continued reassessments should not be necessary.

6. *Community care has not been as inexpensive as promised by supporters (possibly because of high unit costs, given lower than expected patient populations).* Depending on what treatment is actually provided, the unit costs for treating AIDS patients may not be higher than projected. However, initial data from the Hawaii AIDS waiver suggests that community-based care may be more expensive than originally projected. We will simply have to await better data before reaching a conclusion.

7. *Community care is difficult to make cost-effective because of its limited capacity to produce health status change.* Nothing we know

about AIDS so far suggests that anything more than short-term amelioration is possible. Except for some pharmaceuticals, nothing changes an AIDS patient's health status. Nevertheless, the availability of community-based services and volunteer labor reduced substantially hospital LOS for AIDS patients (Arno, 1986). Given community support services, the costs of treating AIDS patients can be reduced because these services help keep patients out of the hospital (Scitovsky, Cline, and Lee, 1986).

Some AIDS literature suggests that community-based care for AIDS patients will be more cost-effective than institutional care. For example, Arno (1986) argues that the hidden subsidy of volunteer labor in providing community-based services and the reduction in hospital LOS as a result of added community-based services will lead to more cost-effective care. The problem with this analysis is that the supply of volunteer labor is not inexhaustible, is subject to burnout, and is particularly organized in the San Francisco market studied by Arno. How volunteer labor is valued is also important: Is such labor a "gift" from volunteer to patient, a subsidy, or an exchange of value (that is, the volunteer's gratification for patient's relief)?

More than anything, this analysis of Weissert's (1985) article raises several research questions to which we will return below. For now, it is sufficient to state that these seven reasons may not all be applicable to AIDS patients, although we cannot say at this point that they are inapplicable.

IV. OTHER RESEARCH RELATED TO THE 2176 AIDS-WAIVER PROGRAM

Among the burgeoning number of research projects related to AIDS policy, two have particular bearing on the questions we are addressing: a survey done by the National Governors' Association (NGA) and a study done by the GAO.

In the fall of 1988, the NGA surveyed all Medicaid agencies to determine the services and programs available for AIDS patients through each state's Medicaid program. Medicaid agencies in each state were asked about the numbers of patients with the human immunodeficiency virus (HIV) infection who were receiving or had received Medicaid services, about Medicaid expenditures (by type of service, if possible) for these services, about the types of program initiatives the agency had adopted or had considered adopting for providing services to HIV-infected patients, and about AIDS-related research efforts then under way. The NGA reported the results of this survey in a March 1989 issue brief, addressing case identification methods, numbers of Medicaid recipients with the HIV infection, Medicaid expenditures for patients with the HIV infection, state coverage of AZT under Medicaid, and state initiatives under Medicaid.

The GAO studied the AIDS populations in five U.S. cities—Baltimore, Seattle, Philadelphia, New Orleans, and New Haven—to determine what services were available and how they were developed and financed. An estimation of the Medicaid program's role in providing services is an important part of this study. However, the study results have not yet been released.

V. CURRENT STATUS OF AIDS WAIVERS

States are categorized regarding their current AIDS waiver status as follows:

- States with approved AIDS waivers or an operational program;
- States that are using a model waiver to provide services to AIDS patients; and
- States without operational AIDS waivers, including states that are currently developing an application for submission to HCFA and states that are not planning to apply.

Our discussion of each category is based on the study design and methodology described in this report's introduction.

STATES WITH OPERATIONAL 2176 AIDS WAIVERS

As of January 1, 1989, six states had operational AIDS-specific 2176 waivers. New Jersey received the first approved waiver with a starting date of March 1, 1987. New Mexico was second (July 1, 1987), followed by Ohio (January 1, 1988), Hawaii (March 1, 1988), South Carolina (August 1, 1988), and California (January 1, 1989). Except for Hawaii and California, each of these states' programs is currently operational. According to spokespersons at BERC, as of January 27, 1989, no state applications for AIDS waivers are pending HCFA action, although several states are considering applying for a waiver.

In the following discussion, we will discuss these programs in terms of their characteristics, experience, benefits, problems, and recommendations for improvement.

Characteristics of the AIDS Populations

Table 3 shows the total number of AIDS cases diagnosed since June 1981 in the waiver states. Waiver states include those in both the top and bottom quartile of numbers of reported AIDS cases.

Similarly, the subpopulations affected by AIDS differ from state to state (see Table 4). Both the homosexual/bisexual and the intravenous drug user (IVDU) populations are unevenly distributed in the states. Although we currently lack complete data for the waiver states, the incidence of AIDS generally differs by age categories and by racial and

Table 3

REPORTED AIDS CASES IN WAIVER STATES
AS OF DECEMBER 31, 1988

State	Total Cases Reported since June 1981	Rank among States Reporting AIDS Cases
California	16,821	2
New Jersey	5,673	5
Ohio	1,137	13
South Carolina	370	27
Hawaii	291	30
New Mexico	145	39

SOURCE: Centers for Disease Control, *AIDS Weekly Surveillance Report*, December 26, 1988.

ethnic groups. However, the incidence of AIDS among racial and ethnic groups may be disproportionate to the numbers of those groups within the larger population. We know, for example, that a disproportionately high percentage of IVDU AIDS patients are found in the black and Hispanic populations.

In Hawaii, New Mexico, and Ohio, the largest affected subpopulation to date is the homosexual/bisexual male population (see Table 4). South Carolina estimates that half its AIDS population is homosexual/bisexual. In contrast, the IVDU is New Jersey's largest subpopulation, accounting for 56 percent of the reported cases. New Jersey also has the dubious distinction of having the second highest number of children diagnosed with AIDS, behind first-ranked New York, which does not have a 2176 waiver.

Scope and Coverage of the States' Medicaid Programs

The Medicaid program, as a joint federal-state endeavor, has some common program elements across all participating states but differs by state in the scope and number of optional services offered (see Table 5). Federal funds comprise at least half of every Medicaid dollar and are distributed on the basis of a state's per capita income.¹

¹The match rate may drop below 50 percent if a state is sanctioned for high rates of fraud and abuse under the provisions of OBRA 1981. States may also choose to offer state-only optional services, but these services must be supported entirely with state general revenue dollars; federal match is not available for these programs.

Table 4

DISTRIBUTION OF AIDS AMONG SUBPOPULATIONS,
 OCTOBER-DECEMBER 1988
 (Percent)

Subpopulations	State					
	Calif.	Hawaii	N.J.	N.M.	Ohio	S.C.
Homosexual/bisexual	(a)	82	28	97	73	50
Intravenous drug users	(a)	3	56	(a)	7	19
Homosexual/intravenous drug users	(a)	2	(a)	(a)	7	~ 7
Hemophiliac	(a)	<1	3	(a)	4	(a)
Transfusion	(a)	2	(a)	(a)	3	(a)
Heterosexual	(a)	2	8	(a)	3	(a)
Pediatric	(a)	<1	3	(a)	(a)	(a)
Race						
Black	(a)	2	45	4	0	54
Hispanic	(a)	4	15	27	22	0
White	(a)	72	39	64	78	46
Other	(a)	20	2	5	0	0

SOURCE: Telephone interviews with Medicaid 2176 waiver staff.

^aNot available.

Each state must offer a core set of services, such as inpatient and outpatient care. In addition, states can offer up to 30 optional services, including prescription drugs and optometry. States also have the option of offering Medicaid services to their medically needy populations.

The comprehensiveness of the Medicaid programs in each of the waiver states varies considerably. California, for example, is renowned for the generous array of 29 optional services available under Medicaid; New Jersey is close behind with 28 services; Ohio is third, with 25 services. Hawaii, with 22 optional services, is close to the mean of 23 optional services offered among these six states, while South Carolina, with 17, and New Mexico, with 16, are at the lower end. Among the AIDS-waiver states, California, Hawaii, and New Jersey have Medicaid programs for the medically needy.

Table 5

AIDS POPULATIONS AND AVAILABLE OPTIONAL MEDICAID SERVICES: WAIVER STATES AND SELECTED NONWAIVER STATES

AIDS-Waiver States	No. of AIDS Patients 12/88	Rank in Reported No. of Cases 12/88	Fed. Match Rate 1985 (Percent)	No. of Optional Medicaid Services	Medically Needy Program
Calif.	5919	2	50.0	29	X
Hawaii	105	29	50.0	22	X
N.J.	2533	5	50.0	28	X
N.M.	59	38	69.4	16	
Ohio	529	12	55.4	25	
S.C.	172	26	73.5	17	
<hr/>					
Non-AIDS-Waiver States					
Conn.	427	15	50.0	24	X
D.C.	512	10	50.0	25	X
Fla.	2714	3	58.4	17	X
Ga.	800	8	67.4	13	
Il.	1032	6	50.0	27	X
Mass.	711	9	50.1	30	X
Md.	552	11	50.0	17	X
Mich.	457	17	50.7	26	X
N.Y.	6938	1	50.0	26	X
Penn.	890	7	56.0	16	X
S.D.	7	49	68.3	16	
Tex.	2239	4	54.4	15	
Utah	75	37	70.8	26	X

SOURCES: Centers for Disease Control, *AIDS Weekly Surveillance Report*, December 1988; Health Care Financing Administration, *Medicare and Medicaid Data Book*, Pub. No. 03247, 1986; *Medicaid Source Book: Background and Analysis*, Congressional Research Service, November 1988.

Motivations for the AIDS 2176 Waiver Application

The six AIDS-waiver states include both those ranking high in the number of reported AIDS cases and those with a much lower number of AIDS cases among their total populations. Perhaps the most important factor in each state's decision to seek a waiver was the projection of its future AIDS population, based on incidence and prevalence data

available in 1986 and 1987. Hawaii, New Mexico, and Ohio indicated that these early projections of AIDS patients likely to need Medicaid services over the next several years were sobering indeed; they recognized that they could meet such potential needs only with concerted advanced planning involving as many service providers and decision-makers as possible.

Several states pursued the waiver option because state officials were committed to providing the broadest array of health services possible to their residents. Others were looking for mechanisms to offer services to a unique population. All the states (with the possible exception of Ohio) had AIDS task forces to advocate for the needs of this emerging population.

An AIDS-specific waiver was financially attractive for those with a high federal financial participation rate, because their more modest state contribution permitted them to draw in additional federal dollars with which to develop programs specifically for the AIDS population. An additional financial motivation for all states was avoiding the considerable costs of institutionalization in favor of services that could, presumably, be offered to the AIDS population less expensively and more appropriately in the home or community setting.

Services Provided under the AIDS 2176 Waiver

Table 6 identifies the services provided to AIDS patients by the six AIDS-waiver states. Hawaii, with 13 services targeted to AIDS patients, will offer the widest array of services; Ohio, with 12 services, is second in scope. New Mexico, with five services, has the narrowest range of services among the six states. Five of the six states cover case management, personal care, and adult day care as part of their waiver services; four of the programs provide some additional services for foster children and/or their parents.

Although the waiver programs have been instituted for only a short time, we asked program administrators about their experiences with this range of services, and what services they would consider adding or terminating when they amend or renew their waivers. The answers varied by state. New Mexico staff members, for example, were assured in preparing their application that transportation to medical services would be provided by an AIDS support group, but the support group has not followed through on its commitment. Therefore, New Mexico would consider adding transportation services in the future. Hawaii, though its program is not yet operational, is considering changes in its proposed services for drug addicts; Hawaii waiver staff's conversations with New Jersey waiver staff have alerted the former to the enormous

Table 6
SERVICES PROVIDED UNDER AIDS WAIVERS

Services	States					
	Calif.	Hawaii	N.J.	N.M.	Ohio	S.C.
Case management	X	X	X	X	X	
Homemaker	X			X	X	
Home health aide						
Personal care		X	X	X	X	X
Adult day care		X	X	X	X	X
Habilitation		X			X	
Respite		X			X	
Services for the chronically mentally ill						
Other						
Adaptive/assistive equipment					X	
Attendant care	X					
Counseling/training			X			X
Nutritional					X	
Psychological	X				X	
Emergency alarm response system	X					
Home delivered meals		X			X	X
Hospice						X
Medical supplies					X	
Minor home adaptations	X					
Moving assistance		X				
Narcotic and drug abuse treatment		X	X			
Private-duty nursing			X	X		X
Screening/assessment						
Skilled nursing facility	X	X				
Supervision/supplement for foster care children	X	X	X			X
Transportation		X			X	
Total	7	13	6	5	12	7

expense of attempting to provide methadone treatment in the home (since it must be administered by a physician). South Carolina has appointed a task force to study its scope of services as the state gains more experience with its waiver.

New Jersey would like to eliminate the AIDS/AIDS-related complex (ARC) requirements (that is, the need for a diagnosis) so it might serve

all seropositives. New Jersey would also like to include hospice care (which is not covered by Medicaid in the state), and would like to see more SNFs and boarding homes for AIDS patients. As an alternative, New Jersey is considering adding respite care (for 30-day coverage). The state feels a need to develop home services for adolescents, perhaps even arranging for special homes.

Experiences in Administering and Monitoring the Waiver

We asked waiver states to describe their experiences in administering the waiver program, focusing on operational issues and comparisons between initial projections and actual experience. Of the six approved waivers, only four have been in operation long enough for states to comment on their experiences. Hawaii's waiver was approved for operation in March 1988 (later changed to April 1988), but the state has had difficulties in contracting with providers and will not be operational until April 1989. California's waiver became operational on January 1, 1989, so the state has little experience to report to date.

Hawaii's difficulty in becoming operational is noteworthy. The Hawaii Medicaid agency initiated its application planning process with AIDS care providers from the community and believed that the state had reached a consensus on the nature and scope of the Medicaid program. The Medicaid agency planned to contract out all services except case management. When the time came to develop contracts, however, the Medicaid agency found that facilities and institutions were reluctant to enter into contractual relationships. One factor, addressed more fully below, was financial: The amounts the agency had allocated for personnel costs were not reflective of the current market. Another factor was that provider organizations were fearful of being "branded" as the AIDS institution, frightening off other types of patients. Apparently those individuals representing providers did not have the authority to commit the agencies they represented to contractual arrangements for care.

As one measure of experience with a waiver, we asked states to assess the accuracy of their projections of costs, costs savings, and patient utilization against their actual experiences. In every instance, the projections for utilization considerably exceeded the actual utilization. Table 7 indicates the projected use for the three-year waiver period and, where applicable, the actual experience for the first year.

Two cost-related issues held true across all states. First, attempting to achieve budget neutrality through use of the required formula was challenging at best. States find the formula complex. They may have no precedent for deriving costs for services to be offered in the home or

Table 7

PROJECTED AND ACTUAL UTILIZATION OF 2176
AIDS-WAIVER SERVICES

State	Number of Persons Served			
	Year 1 Projected	Year 1 Actual	Year 2 Projected	Year 3 Projected
California	788	(a)	963	1138
Hawaii	165	0	298	528
New Jersey	350	237	600	1000
New Mexico	75	48	75	~200
Ohio	47	12	77	~100
South Carolina	500	~250	(a)	(a)

^aNot available.

community, as opposed to costs for services offered in an institutional setting. New Mexico, for example, had only inpatient acute care costs as a standard, because long-term care facilities in that state refuse, on the basis of licensure regulations, to admit AIDS patients. Medicaid staff knew that the projected costs were high because AIDS patients need not be hospitalized for many phases of their illnesses, but no better data were available. South Carolina struggled with a way to cost out all the extra services that foster parents would provide to AIDS babies (but not to other foster care babies), without resolving this issue satisfactorily.

The second cost issue relates to personnel costs for providing services. The nursing shortage and the commensurate increase in nursing salaries needed to secure staff have been problematic for Medicaid agency contractors who based their prices on the then-current market. This has been an acute problem for Hawaii. Both Hawaii and South Carolina have experienced difficulty in finding and retaining personal care aides, and the low wage they are able to pay is a primary factor. Even though Hawaii trains personal care aides, few training slots have been filled. Staff there suggested that the certification requirements for aides mandated by the 1987 OBRA will only exacerbate this problem.

Of those states for which data are available, New Mexico appears to have most closely met its projections, providing services to some 64 percent of the number of clients it projected it would serve. New Mexico's slots are "replacement" slots, meaning that it can only serve

up to 75 patients at any one time. In Hawaii and Ohio, the numbers projected to be served are "ceiling" figures; once those numbers are reached, services cannot be provided to others without amendments to the waivers.

States offered several reasons for the differences between their projections and the actual utilization. Hawaii's early projections were based on Centers for Disease Control data. Although the state has not yet served any AIDS patients, the total number of AIDS patients diagnosed in Hawaii between June 1981 and December 1988 is 291, suggesting that its projections for the first year may be high. In Ohio, waiver staff suggest that at least two factors have influenced utilization. The first is that families and others appear to feel more responsibility, and are more willing to care for AIDS patients, than was earlier anticipated. According to the Ohio waiver staff, this change in behavior and attitude may be attributed in part to an increasing understanding and awareness of the disease, at least among those most directly affected by it. A second factor appears to be the ameliorative effects of the drug AZT, through which symptoms are suppressed, or at least delayed. These ameliorative effects mean that fewer services may be necessary in the disease's early stages and AIDS patients may stay at work and keep their private health insurance longer.

The independent evaluations required of the AIDS 2176 waiver, when they are available, may provide further insight into the states' experiences in administering and monitoring the waiver.

Benefits of the 2176 AIDS-Waiver Program

States identified several benefits they believe derive from the 2176 waiver. The AIDS-specific waiver provides a focus for care for AIDS patients within the Medicaid program, allowing an agency to target appropriate services to this population without having to provide similar services on a statewide basis. New Jersey, the most experienced AIDS-waiver state, credits its waiver program for the following benefits:

- Establishing a uniform system of services;
- Establishing an AIDS treatment network;
- Identifying and rectifying gaps in service delivery;
- Providing home care and greater access to AIDS patients;
- Providing new services such as foster group homes for children;
- Providing flexibility in service design and delivery; and
- Expanding financial eligibility for AIDS patients to up to 300 percent of SSI levels.

Ohio points out that its waiver program, by focusing on in-home services, improves AIDS patients' quality of life and is more sensitive to the patients' wishes than is institutional care.²

Problems with the 2176 AIDS Waiver

The limited number of states with an operational waiver and the relative newness of this particular waiver limit the basis on which to analyze comprehensively problems with the waiver process. Nevertheless, in our discussions with these states, we identified some problem areas or potential problems areas that might suggest why some states pursue the waiver option and others do not.

In the words of one state administrator, waivers are only an instrument—and perhaps not the best instrument—to permit a state to devise particular programs to serve special populations. The application process as well as program administration, monitoring, and reporting all require considerable staff resources. Working through the cost-effectiveness formula posed difficulties for several, if not all, of the states. However, Medicaid staff were quick to comment that HCFA staff were very responsive and were clearly committed to approving the application if at all possible.

Despite these problems, states indicated that based on their experience to date, they would renew their waivers at the end of the first three-year approval period. They are already considering adjustments they will make and amendments they will seek to permit greater flexibility in their programs.

Recommendations to Other States That May Be Considering a Waiver

Although the most veteran state has less than two years' experience with this waiver, states offered two major recommendations to their counterparts considering the waiver option. The first is to understand very well both the target populations to be served and the provider community so that the application accurately reflects the populations' needs and the providers' commitments. The second recommendation is to design the waiver for maximum flexibility so that all appropriate patients can benefit from the services offered with a minimum of bureaucratic adjustment and paperwork.

²Clinkscale (1988b) notes that waivers have the added benefit of covering both nonmedical and medical services to meet long-term care needs.

STATES USING MODEL WAIVERS TO PROVIDE SERVICES TO AIDS PATIENTS

At least two states, Illinois and North Carolina, use a model waiver to provide services to AIDS patients. The model waiver, as described above, permits a state to target special services to as many as 200 individuals with similar conditions. In Illinois, a model waiver was approved in June 1988—with an effective date of July 1, 1988—to provide home health aides, respite care, environmental modifications, private duty nursing, and special medical supplies. This waiver also covers equipment and appliances to ventilator- and other technology-dependent patients, and to children with AIDS.

North Carolina uses a model waiver to cover the expenses of children who need long-term care but can only receive this care in an acute care hospital because nursing homes will not accept them. The Medicaid agency extended the definition of children eligible for the waiver services to those who have AIDS or ARC. To date, one child has received (and continues to receive) services under this waiver. A second child died before eligibility could be determined.

However, the state does have a broad range of Medicaid optional services, including private-duty nursing, with few limits on such services (unlimited home health care visits, for example, and a recently added hospice option). It is also considering adding case management as an optional service rather than applying for a waiver.

North Carolina has three other waiver programs, as well as a task force on AIDS, but has not yet applied for an AIDS-specific waiver because of concerns about the application process. The waiver application and renewal processes, in its view, are demanding and cumbersome; the state has few personnel to administer waiver programs, and securing an independent auditor to carry out the monitoring and reporting responsibilities is also too burdensome.

STATES WITHOUT OPERATIONAL AIDS WAIVERS

As this report's introduction described, we contacted several states to discuss the reasons why they plan to apply for a waiver or the reasons why they did not plan to apply. Our survey of states without an operational AIDS waiver generated information on five states—Connecticut, Florida, Georgia, Pennsylvania, and Texas—that are developing 2176 AIDS-waiver applications. Perhaps most important, the states we contacted expressed general approval of the substantive AIDS-waiver program as the best approach currently available for serving AIDS Medicaid patients. Although the incentive of additional

federal dollars and expanded eligibility standards cannot be ignored, it seems clear that most states view the program content favorably. The program facilitates eligibility and provides a package of services that cannot be replicated under many state plans.

The Waiver Application Decisionmaking Process

Reasons for Not Applying. For HCFA's purposes, focusing on the reasons states give for not submitting an application to the 2176 program is perhaps most important. The nonwaiver applicant states in our survey did not complain about the program content. Instead, states not interested in applying for the waiver raised several broad objections.

To begin with, almost every state complained about the application process itself. Even discounting traditional state desires to be free of federal interference in state programs, the breadth and intensity of the objections suggest more than simple carping. More than one state suggested, for instance, that the administrative burdens outweighed the program's benefits (and the influx of federal funds), even where the states valued the substantive program.

Many program administrators stated that the process was much too long and that adequate information could have been obtained with less paperwork and justification for each detail. For example, Michigan rejected the 2176 application as a policy option because experience with other waivers suggested burdensome administrative requirements, particularly the cost reports, excessive questioning about details, and insufficient latitude for the states (in the form of justifying each program detail). A common refrain on the administrative costs of the 2176 program was that given the total waiver population percentage, the amount of staff time and resources allocated to administration and reporting was out of proportion to total spending for the home and community-based waiver. States lack administrative funds to run the program, but administrative costs cannot be incorporated into the current program.

Another consistently expressed concern was the need for greater flexibility in program administration (see Pascal, Cvitanic, Bennett, Gorman, and Serraton, 1989). Several states suggested that the reason more states do not apply is that the program does not allow sufficient state innovation. Not all states hold this view, though most would like to experiment with additional services and different administrative structures.

The cost-effectiveness justification, including the cost reports, received repeated and harsh criticism, as did the length of time to

complete the process. Even states that ultimately decided to apply raised these complaints. Indeed, many were frustrated that much of their time was being spent on the cost-effectiveness formula instead of developing appropriate community-based services. Several representatives suggested that the budget neutrality contemplated by Congress has become a need to show cost savings in implementation. On at least one occasion, a state felt pressured to show cost savings, not merely budget neutrality, in completing the application. As a result, some states maintain that HCFA is placing too much emphasis on cost savings and not enough on improving the mix and quality of services. Whatever HCFA's real intentions, the appearance to many states is that cost savings, not innovative program services, must drive the waiver application.³

Several states—especially Massachusetts, New York, and Maryland⁴—failed to apply because they were already providing similar services under state plans. Hence, they felt the 2176 program offered only marginal benefits over what services they were already providing to AIDS patients. To these states, the marginal programmatic benefits were offset by the added administrative costs and diminished program flexibility. These states determined that they could retain greater administrative freedom by providing services to AIDS patients under other programs (such as expanding their optional Medicaid services).

In particular, New York offers a comprehensive array of home and community-based services under its state plan, sometimes going beyond 2176 coverage, and new legislation has been introduced to provide additional services. For example, AIDS patients in New York are also eligible for the respite care waiver for the aged and disabled, or for nursing home coverage. New York has added hospice coverage (available to AIDS patients) and will include case management for AIDS patients.

This is not to suggest that these states are without problems in serving AIDS patients. In New York, for example, problems with provider

³This attitude toward cost savings is in direct contrast to expressed HCFA views. At the Sixth Annual Meeting on Home and Community-Based Waivers, HCFA officials noted that assessing the waivers on the basis of costs avoided as a result of the waiver is more accurate. BQC officials, for example, noted that in fiscal year 1987, cost avoidance totaling \$314,146,078 was found in 63 waivers reviewed. (We have no information, however, as to how this estimate was derived or exactly what costs were avoided.) This figure represents dollars that were not required to be spent (that is, costs avoided) on institution-based services because services could more effectively be provided in the home or community. However, it does not necessarily follow that this sum would have been spent on providing institutional services in the absence of a waiver.

⁴Maryland appears to be a special case because strict cost containment limits overall expenditures, hence limiting the ability to purchase additional services. (One source, however, suggested that this calculation resulted from poor data, and that when better data are analyzed, an application is likely.)

participation occur. Because of insufficient provider participation, particularly among nursing homes, AIDS patients have reduced access to the appropriate level of care. Although states could simply expand their optional services, many stressed financial and political barriers to doing so. Nonetheless, most covered AZT under the federal grant program.

As we expected, the two sample states with a low AIDS incidence have not seriously considered a 2176 waiver. It is also unlikely that many low AIDS-incidence states will consider one in the future, without an increase in the AIDS population. One reason for this is that these states can provide necessary services to the current AIDS population. In Utah, for example, AIDS patients are eligible for all Medicaid services, including home health and nursing home services, with a physician acting as a case manager.

Reasons for Applying. Although the reasons for planning to submit an AIDS waiver application vary across states, one consistent motivation is programmatic. Each state planning to apply stated that it expected to provide a broader array of services more efficiently under the waiver.

In some states, the motivation is as much political (that is, they are under pressure from AIDS advocacy groups) as it is programmatic, since few states really expect significant cost savings. In other states, the primary motivations are programmatic. In Texas, for instance, the state is looking for greater efficiencies and a more appropriate array of services for unmet needs. Faced with restrictive nursing home admissions, restrictive home health requirements, and no case management, the waiver program in Texas should provide alternatives to hospitalization for AIDS patients.

Likewise, Connecticut AIDS patients face an inadequate range of available services under current optional services, and an application is awaiting approval from state officials. An application will be submitted from Florida because the state feels that the waiver program is the best approach to the problems. As a result, the state expects to offer a wide range of available services. Georgia also finds the array of available services substantively attractive. Its application is pending before the state legislature.

Program Concerns

States were not at all reluctant to share their concerns about the waiver program and to offer recommendations for improvement. Some of those concerns and recommendations have already been intimated in the above discussion but need amplification to provide HCFA with a basis for considering changes in the program's structure or approach.

Revising the Cost-Effectiveness Formula. Probably the most consistent and insistent concern expressed by the states was the need to redesign the cost-effectiveness formula. If states use the existing formula, which assumes that each person served under the waiver will require institutional services, the ability to divert a certain percentage from some amount of institutional care should result in showing cost savings. In short, the current formula does not necessarily represent accurate cost savings in fact. If the formula is changed to reflect more realistic assumptions, more accurate estimates of cost savings can be developed.

As a result, many states suggested that cost savings in this program are illusory, achieved only on paper. This suggestion reveals skepticism that the current formula is workable, or that the 372 form is an accurate representation of cost savings. Even states most in favor of the program had doubts about true cost savings—an especially significant fact in view of the staff resources allocated to ascertaining and detailing projected cost savings. One state, for example, has spent some 18 months satisfying the cost-effectiveness formula. The formula itself is a major problem; a new, understandable formula using state system data to determine costs with and without the waiver was suggested by several states. These states complained that the cost formula does not take into account different state data systems, and requires estimates and data not maintained in the form needed for the formula.

An alternative model suggested by several states is to use the approach set forth in Section 1915(d) of the Social Security Act (42 USCA 1396n[d]), entitled Home and Community-Based Services for the Elderly. This section simply expands the availability of waiver services to individuals over 65 years of age who would otherwise require institutional services. However, this section deletes the cost-effectiveness formula in favor of an approach based on total annual state expenditures for medical assistance for nursing homes and community-based care. As long as total expenditures remain within defined limits, calculated on base-year expenditures as adjusted for inflation, states can allocate funds between nursing homes and community-based services as appropriate. In essence, this procedure allows considerably greater flexibility to the state in designing its programs, without showing how each waiver service is cost-effective. Although currently limited to home and community-based services for the elderly, the approach appears equally applicable to AIDS waivers.

Finally, states seem confused about substituting inpatient care for the long-term care elements currently in the formula. HCFA should either clarify the formula values for the AIDS waiver or devise a separate formula applicable only to the AIDS waiver.

Administrative. Most of the states' administrative concerns have been set forth in the application process discussion and will be reiterated in our recommendations below.

Although not a prevalent problem, inconsistent instructions between Baltimore and the regional offices were commented on by more than one state. Most often, this problem appears to result from complicated written instructions that may differ from what states are told verbally. To the states' apparent dismay, HCFA seems to promise interpretive flexibility, but responds with restrictive interpretations. Thus, HCFA should ensure that the regions and headquarters are interpreting the regulations consistently.

Programmatic. The most common programmatic need expressed was for some form of bed and board care, although no waiver program covers this service.⁵ Providing beds is a major concern, especially in states with high IVDU and/or homeless populations. An unmistakable need exists for nursing homes to take patients with AIDS—or at least for some overnight care. Without a large pool of volunteer labor and nursing home beds, states are unlikely to reduce costs because the realistic alternative to home care at certain stages of illness is hospital care, and many AIDS patients have inadequate home or community-based care.

Several states would like HCFA to consider adding more nonmedical services for AIDS patients as a way to serve the AIDS population more effectively, arguing that if states are willing to do so, Medicaid should provide any service (whether social services or medical care) on an as-needed basis. Massachusetts and North Carolina, among others, would like to add a housing component. Similarly, Pennsylvania would like to expand the program to room and board for a residential facility. One recommendation is that if the program is cost-effective relative to institutional care, Medicaid should pay for room and board in a residential facility. As Illinois said, "no home, no coverage," so a homeless IVDU could easily fall through the cracks in the delivery system. These proposals, however, are controversial and may be instances of wishful thinking rather than realistic recommendations.

An important state concern involves service to persons in the community who might require an inpatient level of care, as well as to patients who are already institutionalized. This concern is important,

⁵Despite state requests for assistance with housing and nonmedical services through the Medicaid program, such expansion would represent a major change in the Medicaid program as currently structured. Since states make the point that failing to provide such services actually increases Medicaid expenditures, considering a small demonstration project for a discrete AIDS subpopulation, such as homeless IVDUs, might be worthwhile.

because a problem for some AIDS patients is the level of care⁶ requirement for 2176 program eligibility. Under a strict interpretation, the patient must leave the program when the overall functional level improves because he or she is no longer level-of-care eligible. During the course of illness, the typical patient will experience periods where no medical care is necessary, thereby losing valuable benefits (Pascal, Cvitanic, Bennett, and Serrato, 1989). Several states want a flexible interpretation that allows AIDS patients to remain eligible once a level-of-care eligibility is determined (despite periodic improvements). To take persons on and off the waiver is an administrative nightmare for a state and difficult to explain to a beneficiary. Once certified, states argue, an AIDS patient should remain eligible. To decertify the program or remove individuals from 2176 coverage would be counter-productive.⁷

Several states want HCFA to pay for more database development. In particular, Maryland wants money to link ICD-9⁸ codes to AIDS registries for better cost estimates and more effective program management. As suggested above, this program presents an opportunity for HCFA to develop standardized data collection methodologies. For example, data on services provided (such as the number of inpatient days before and after waiver implementation) to both AIDS waiver and AIDS nonwaiver patients will assist additional research efforts in evaluating the waiver program's effectiveness.

DISCUSSION

As a general recommendation based on the above comments about the application process, most states suggest that HCFA should require a broad general program description with a bottom line for total expenditures and let the state figure out how to allocate funds and services. The larger question is whether HCFA is selling the program on the wrong issues, particularly since the states seem to like the program

⁶That is, the patient must meet certain functional status indicators to be eligible for institutional care.

⁷To the extent that the Tax Correction Act of 1988 (see Congressional Record, H 11000, October 21, 1988, Section 8436) has been implemented, this issue has been resolved. This provision amends Section 1915 of the Social Security Act to allow states to cover persons in the community who meet level-of-care requirements (that is, who are expected to need institutional services). Paradoxically, according to Florida, this will increase the state's burden in showing cost-effectiveness. If serving the institutionalized population, data may be used for that group alone, but if serving populations diverted from institutional care, statewide data must be used (making showing cost-effectiveness more difficult).

⁸*International Classification of Diseases, 9th ed.*

substantively. Programs must be developed with the specific needs of AIDS patients in mind, which often means meeting nonmedical needs. The problem is to match services needed by AIDS patients to those available under the 2176 program. In sum, states recommend that HCFA should move back to considerations of budget neutrality, program services, and quality, and away from the focus on cost savings.

Based on the state discussions, it seems clear that state representatives are all searching for better ways to deliver services to AIDS patients. Accordingly, it is important for HCFA to continue to act as a clearinghouse for keeping the states informed about new developments in services to AIDS patients.

Comparisons between Waiver and Nonwaiver States

Although each state decides whether to apply for an AIDS waiver based on factors that vary across states, certain generalities seem warranted. In general, states with a greater AIDS patient population seem more interested in the 2176 waiver program than states with few AIDS patients. And states with extensive benefit programs already operating seem less interested in the application process (even if they have a high AIDS population).⁹

However, comparing the level of services provided by nonwaiver states to those provided under a waiver is difficult. Although nonwaiver states insist that they provide a broad array of services to AIDS patients, differing eligibility requirements and somewhat differing services make comparisons difficult. Also, AIDS waiver services are targeted to AIDS patients; nonwaiver services are directed to all Medicaid patients. This is an important research question, which we will discuss below.

When the expressed reasons for not applying are compared to the perceived benefits of currently operating AIDS waivers discussed above, an interesting anomaly emerges. One of the primary benefits mentioned by current waiver states is the program's flexibility. Yet a primary reason why states do not apply is a perceived lack of flexibility.

This anomaly suggests that waiver and nonwaiver states have different understandings of what services can be provided. Some nonwaiver states, for instance, suggested that nonmedical services were just as important for AIDS patients; yet these states felt they could not

⁹The 13 states we contacted fall into two groups with regard to optional services: 7 states (Connecticut, Florida, Georgia, Maryland, Pennsylvania, South Dakota, and Texas) offer between 13 and 17 optional services, with the average being 16; 5 states (Illinois, Maine, Michigan, New York, and Utah) and the District of Columbia offer between 25 and 30 optional services, with the average being 27. Of these 13 states, 10 have medically needy programs. Among the latter group, only Illinois has or is considering an AIDS-waiver program.

be provided under the waiver. From the list of services offered by the AIDS waiver states (Table 6), it is clear that at least some of these services (such as transportation), though facilitative in nature, are not strictly medical services.

This situation presents HCFA with an opportunity to alter the perceived lack of flexibility and to clarify the range of available services. Although the applicable regulations (42 CFR 440.180) clearly permit "other services," the range of other services is not defined in HCFA's *State Medicaid Manual*. As one way of reassuring reluctant applicants that their concerns can be addressed, we suggest that HCFA revise its definition of services in the manual (Section 4442.3) to provide general guidance as to which other services a state may provide.

Finally, considerable variation exists across states as to data availability. Some states have devised sophisticated data collection systems on the number of AIDS patients and services provided, while others have not even begun to collect adequate data. This variation presents a short-term problem in comparing programs across states and measuring outcomes, and a longer-term opportunity for HCFA to develop a consistent data methodology.

Special Population Groups

The states did not indicate a particular problem with special population subgroups beyond what we might expect (see, for example, Table 4). That is, only a few states identified special needs for population subgroups. As far as we can tell, three reasons for this situation are possible: the numbers are not large enough to have identified separate subgroup needs, these subgroups are provided services along with other AIDS patients, or the states lack information on the problem's scope. Only New York and New Jersey have large numbers of pediatric and adolescent AIDS cases.

As mentioned above, New Jersey—perhaps because it has a more fully developed program—has identified adolescents as a special-needs subgroup. Aside from adolescents, program placement for pediatrics AIDS patients and homeless IVDUs seems the most consistent problem. For example, finding foster care placement for children with AIDS or who are HIV positive is difficult. But as New York notes, the current system's irony is that hospitals, and perhaps nursing homes, are paid at higher levels, although less expensive room and board cannot be paid. In New York, AIDS care centers for pediatrics are under development, but they go beyond medical services. Even though foster care homes should be less expensive, South Carolina has had difficulty in satisfying a cost-effectiveness formula for them.

VI. FUTURE RESEARCH

The following section examines areas in which additional research is needed to increase our understanding of Medicaid's role in providing effective services to AIDS patients.

COMPARISONS BETWEEN POPULATION GROUPS AND PROGRAMS

The waiver program's nature lends itself to several potentially interesting comparisons across states and between programs within states. Based on our discussions with the states, four potential service utilization research issues should be considered: (1) comparisons between AIDS patients and other waiver populations; (2) pre- and post-2176 AIDS-waiver comparisons within states; (3) AIDS-waiver populations compared to nonwaiver AIDS populations (including comparisons between AIDS Medicaid and non-Medicaid populations and comparisons between AIDS subpopulations); and (4) comparisons between waiver and nonwaiver states.

Comparisons between AIDS-Waiver and Other Waiver Populations

In planning this project, we assumed that a natural follow-up research project would be to compare AIDS-waiver and other waiver populations. Given the similarities in program design, a research question would be to determine relative cost-effectiveness and quality of care between these programs. Most states, however, suggest that comparisons between AIDS waiver populations and other waiver populations are misdirected.

Clearly, certain similarities to other chronically ill patient populations in costs and need for home and community-based services exist (see Benjamin, 1989), but the episodic and terminal nature of AIDS is different from the long-term care needs of other chronically ill patients. With elderly waiver patients, a plan for care will remain relatively stable over time, while needs vary from week to week with AIDS patients. Thus, most states argue that AIDS patients are not fundamentally similar to other chronically ill populations. Although this view is not unanimous, we do not recommend additional research on this topic.

Pre- and Post-2176 AIDS-Waiver Comparisons

To determine the waiver program's effectiveness, researchers could compare services delivered, expenditures, treatment patterns, and outcomes for AIDS patients before and after initiating a 2176 waiver. Unfortunately, most states have insufficient data for the pre- and postwaiver comparisons. For the most part, states lack adequate data on specific services rendered and costs of services before the waiver. Further, many of these services may have been provided by sources other than Medicaid. A peculiar characteristic of the Medicaid caseload is that many patients qualified for Medicaid only after undergoing substantial treatment under other reimbursement mechanisms, such as private insurance.

Even where reasonably adequate data exist, such comparisons may also be difficult because data may not exist to make necessary adjustments for differences in the disease process. Many states (such as New Jersey) have data only from the point of diagnosis, making pre- and postwaiver comparisons difficult. (Diagnosis may come relatively late in the disease progression; prediagnosis treatment costs may have been incurred by Medicaid or some other payer.) Florida, however, is developing a diagnostic screen for paid claims history to enable pre- and postwaiver comparisons.

Because of data limitations, we do not recommend a major study of pre- and postwaiver comparisons at this time. But because such comparisons would provide HCFA with important information, we recommend a small project to analyze New Jersey and Florida data. If warranted, the project can then be expanded to other states.

AIDS Medicaid and Non-Medicaid Comparisons

Determining whether AIDS Medicaid patients are receiving different levels of care or treatment and have different outcomes than non-Medicaid AIDS patients is important. A study could be conducted in a sample of the high AIDS-incidence states. As with pre- and postwaiver comparisons, most states have insufficient data for AIDS Medicaid and non-Medicaid population comparisons. Nevertheless, comparisons between AIDS Medicaid and non-Medicaid patients are reportedly included in a Yale/Connecticut Hospital Association study (Stolwijk, Handschumacher, and Thompson, 1988) showing that Medicaid patients may be diagnosed later than private-pay patients and treatment may also be initiated later, leading to a longer LOS but a shorter survival time (with hospital stays characterized by more severe illness). The summary report provided to RAND does not contain sufficient

information to verify these findings. We do not know, for example, whether the findings have been adjusted for differences in risk group and major diagnosis between the Medicaid and private patient populations.

A recent RAND study (Pascal, Cvitanic, Bennett, Gorman, and Serato, 1989), based on research sponsored by HCFA and delivered at the National Center for Health Services Research Conference on Health Services Research for AIDS (Miami, Fla., May 17-19, 1989), also found resource utilization differences between Medicaid and non-Medicaid AIDS patients. For a sample of white homosexual males (holding diagnosis constant), the study found that MediCal (California's Medicaid system) patients had fewer and less costly hospitalizations in the first year after diagnosis for AIDS, compared to patients with private health insurance. The study reported significant inpatient and outpatient resource utilization differences between pneumocystic carinii pneumonia and Kaposi's sarcoma patients.

As part of the Florida diagnostic screen mentioned above, data on Medicaid's average exposure for claims may be a base for Medicaid/non-Medicaid comparisons. However, the state anticipates research design problems because patients not eligible for Medicaid have income too high for inclusion in the database. Thus, data from private insurance companies and other sources would be necessary to complete the study. We recognize the difficulty of obtaining such sensitive data in view of confidentiality concerns. However, given the Yale study's results, the preliminary RAND findings, and the potential Florida data system, this area holds promise for meaningful research.

A further comparison is to look at differences between the IVDU population, the gay male population, and AIDS-infected children. What works for one group may not work for another, particularly the separate needs of the IVDU homeless and racial minorities. In view of the shifting demography of the AIDS infection, research can help identify the differing service needs of each subpopulation and the potential for home and community-based care to reach these populations.

Comparisons between Waiver and Nonwaiver States

Another approach to determining the effectiveness of the 2176 waiver program is to compare expenditures, services, treatment patterns, and outcomes between waiver and nonwaiver states. (To the best of our knowledge, no states provide both waiver and nonwaiver services to AIDS patients.) Because of cost concerns and the absence of previous waiver program cost-effectiveness studies, an important future research topic is to conduct such a study for the AIDS waiver.

An important aspect of such a study would be to consider additional costs to the Medicaid program for AIDS patients who, when they become eligible for Medicaid, are thus eligible for any service offered by Medicaid. These additional costs may not have been anticipated in the waiver application process, but waiver states are now concerned about this issue.

Because not all states have AIDS waivers, HCFA has an opportunity to conduct a natural experiment to measure both the effectiveness and cost-effectiveness of the waiver program. Although increasing numbers of the high AIDS-caseload states are applying for waivers, comparisons between New York or Massachusetts and waiver states would provide invaluable information for subsequent program management and policies. Some questions a potential project would attempt to answer include:

- What are the appropriate outcome measures? Are there different outcomes?
- Do hospital admission rates, survival times, and LOS differ between waiver and nonwaiver states?
- What types of services are provided in waiver versus nonwaiver states?
- Are services to AIDS patients in waiver states more effective than in nonwaiver states? Are they more cost-effective than in nonwaiver states?
- What is the level and quality of services provided in waiver and nonwaiver states? Do different eligibility requirements result in different service delivery patterns?
- What are the effects of the new discharge planning requirements on home and community-based programs? Do these effects vary between waiver and nonwaiver states?

ADDITIONAL RESEARCH QUESTIONS

During the course of this analysis, we have identified topics that require additional research to further our understanding of the use of Medicaid resources for AIDS patients. Several of these topics arose in our conversations with Medicaid officials who are implementing or applying for a 2176 AIDS-specific waiver; others derive from the gaps that appeared when we reviewed issues of program implementation and research in progress. We will highlight several other important research questions HCFA should consider.

Research Specifically Related to the Waiver Program

Service Delivery:

- Are particular services more effective than others? For example, should case management services be stressed relative to other services? Is case management a necessary predicate for other services?
- Are particular services more effective for certain population subgroups than others? For example, do IVDUs benefit more from adult day care and personal care services than from counseling services?
- Which services are more effective in keeping patients out of institutions?
- What are the effects of longer survival times on service delivery?
- How effectively do states target services to those who would otherwise use institutional services? Can HCFA develop measures or preadmission screens to determine whether waivers postpone or prevent institutional care? These questions were also raised in the GAO report (1987).
- Can states identify where and how non-Medicaid AIDS patients are being served?

Cost-Effectiveness:

- Will the 2176 program reduce inpatient hospital days or will it simply add costs for outpatient services?
- Are waiver services more cost-effective for AIDS patients than optional Medicaid services?

Quality of Care:

- Do waiver services substitute for inpatient care? New Jersey would be receptive to a comparative study on use by non-Medicaid AIDS patients of hospital services relative to waiver patients and the program's effect on inpatient episodes and patient outcomes.
- What are the waiver program's effects on patient outcomes, survival times, satisfaction, or quality of care?
- How can quality of care for waiver services be measured?

Research Relating to Program Implementation

California providers of services to AIDS patients are concerned that caps on the allowable dollar amounts of services that can be provided

to AIDS patients will result in administrative inflexibility and constraints in offering services. Persons working with the New Mexico waiver also suggest that this could be a problem area. This study's limited scope did not permit us to explore this issue further, but it appears to be one that should be pursued among all waiver states to determine its extent and significance as a potential problem area.

Several sources have noted that patients with ARC pose dilemmas for Medicaid and other funding agencies in terms of services to be provided and reimbursed. Few states seem to have developed specific guidelines for Medicaid services to ARC patients. As a result, services available to this population, particularly those provided through Medicaid programs, need further study.

Research Related to AIDS and Medicaid in General

Beyond the specific questions raised by the waiver program, the increasing Medicaid burden for AIDS patients raises a more general set of questions. We think it important that HCFA consider AIDS not just in the context of waiver programs, but in terms of how service delivery to AIDS patients under Medicaid affects other eligible populations.

For example, what changes have occurred in Medicaid eligibility and service delivery since the AIDS epidemic's onset? How have such changes affected the number of eligibles served, categories of eligibles served, and actual services offered? In particular, what effects have such changes had on the categorically eligible Medicaid populations? What, in other words, is the relationship between the rising Medicaid burden for AIDS patients and service delivery to other Medicaid populations? In particular, has the increased allocation of Medicaid resources for AIDS patients reduced the availability of services for women and children, major original Medicaid beneficiary subpopulations?

Another growing population at risk for AIDS, the children born to parents with AIDS, is an emerging issue for research and policy development. The NGA issue paper (March 1989) reports that 18 states have developed initiatives for pediatric AIDS through their Medicaid programs. The nature of these initiatives, the actual and projected numbers at risk, and the implications for future Medicaid programming and expenditures warrant additional examination.

DATA NEEDS AND SOURCES

To study further the commitment of Medicaid resources to AIDS patients we have identified prospective data sources, including ongoing

studies, for additional exploration and investigation. Current studies are developing data that may be useful to HCFA. In addition, several states have developed their own data collection systems for AIDS patients. The following list is by no means exhaustive; it indicates starting points for future analysis.

The AIDS Policy Center of the Intergovernmental Health Policy Project is collecting data from state budget officers on state resources that are being devoted to the AIDS problem. As of early May 1989, some 30 states had responded to the 18-page survey, but the preliminary results from this survey have not been released.

In addition, in their March 1989 issue brief, "AIDS and Medicaid" (see NGA's Appendix B), the NGA identified the mechanisms used by 31 state Medicaid agencies to identify Medicaid eligibles with HIV. These mechanisms, resulting in an ability to track expenditures for this population, include diagnosis codes, manual claims review, AZT claims review, and the 2176 AIDS-specific waiver.

The research company Systemetrics is studying access for the Medicare and Medicaid populations to AIDS services in response to concerns raised by the National Task Force on AIDS, whose report was released in the summer of 1988. Systemetrics plans to report its findings on issues of eligibility, the disability determination process, and the gray area of ARC in 1989.

To study the AIDS issue's inpatient dimension, NCHSR's Hospital Cost and Utilization Project database provides a unique source for studying on a national basis the admission frequency of patients with AIDS and related conditions, their pattern of morbidity while hospitalized, and variations in treatment they receive across many types of hospitals and all regions of the country.

Finally, during the course of our discussions with states, we were informed of several attempts to develop adequate data systems for monitoring services to AIDS patients under the Medicaid program. Some of these systems—such as those developed in New Jersey, Florida, Utah, and Pennsylvania—might be useful as models for other states. Unfortunately, these attempts are not necessarily interchangeable or consistent with one another for immediate national implementation.

Several data needs are apparent:

- Given the general unreliability of the data, a universal data set and data collection methodology should be developed.
- A standard data design for each state to undertake its mandated evaluation of the waiver program would be helpful.

- A standard and effective preadmission screening instrument is imperative. What data or instruments are needed to identify persons in the community who may need assistance?
- Data are needed to compare survival time and LOS for waiver and nonwaiver AIDS patients.
- Better data on admission rates and LOS for AIDS patients are needed for any meaningful analyses of the waiver program.
- Better data are needed on utilization trends and patterns. At what stage in the disease process do patients enroll in Medicaid (on average)? What is the time span between infection and Medicaid eligibility? How do people come into the public system (that is, what are the referral patterns and eligibility categories)? What is the average length of time on Medicaid? What are the differences in treatment by stage of disease? How does insurance status change over time? These and similar questions were raised by program administrators as being critical. That the states are looking to HCFA to develop systems to answer these questions suggests the inadequate status of current data collection systems.¹
- National data on outcome comparisons between private- and public-pay patients should be collected and analyzed.
- Data should be collected on how states determine presumptive eligibility for AIDS patients (that is, income and asset determinations) and the subsequent determination of eligibility for services.
- A standard data system should track reported changes in eligibility for waiver services to AIDS patients to determine the extent of waiver services' discontinuity and the discontinuity's effects on the patient's health status.

¹The RAND study referred to above has attacked these issues for a small sample of AIDS patients in Los Angeles; it could be expanded for use on national samples.

VII. CONCLUSION AND RECOMMENDATIONS

Although this project was not designed as a cost-effectiveness analysis of the 2176 AIDS-waiver program, the responses from our state survey suggest that the AIDS-waiver program is a promising approach to meeting the health care needs of AIDS patients. Because the actual program experience is so limited, firm conclusions about the program are premature. Nevertheless, our discussions with various state officials indicate considerable optimism that the waiver model can be an effective means of providing services to AIDS patients, especially if the administrative and programmatic changes discussed above are made. Indeed, even states that declined to apply for a waiver were generally not critical of the underlying programmatic waiver approach.

If so, what changes are necessary to make the waiver program more attractive to states? Aside from the research questions outlined above, we offer the following recommendations for administrative and program changes. By adopting some or all of these recommendations, the program can be improved for states now using the waiver and made more attractive to other states. As is often the case in such programs, the most difficult task is finding the proper balance between state autonomy and federal involvement. At this point, that balance appears to be lacking.

Thus, our primary recommendations deal with the need for relaxing some federal administrative requirements in the 2176 program. We believe that these changes will strengthen the program without undermining current cost and program goals. Based on our review, we suggest several possible policy strategies to increase states' interest in the 2176 waiver program. These recommendations are both programmatic and administrative, and follow from our discussion of the reasons why some states have not applied for a 2176 waiver.

- Ease the waiver requirements related to application, administration, and reporting.
- Consider increasing the program's flexibility, especially toward functional status eligibility requirements (away from requiring constant disability) and the range of programs allowable. This would permit states to serve medically needy patients with ARC or HIV-positive patients based on functional, rather than diagnostic, needs. It would also encourage state innovation.

- Relax the requirement that cost savings be demonstrated before a waiver can be granted. Focus equally on the efficiency and quality of service delivery to program clients, as well as on budget neutrality or cost savings.
- Revise the cost-effectiveness formula (perhaps by reducing the justification).
- Reduce the waiver application's processing time.
- Encourage states that have waivers in place to perform ongoing evaluations and provide forums (such as the annual meeting of those involved with administering a state's 2176 waiver program) where their observations can be shared by states without waivers.
- Develop a preadmission screening instrument enabling a state to identify AIDS patients in the community who would otherwise need institutional care.
- Develop standard data collection methodologies for all waiver states, so that across-state variations in service delivery can be determined. HCFA should also revise the 372 data collection forms, taking into account the concerns raised above about the current formula.
- Improve the program's marketing to stress flexibility in service delivery and expanded eligibility. HCFA should serve a clearinghouse function to keep states informed of developments in other programs on a regular basis.
- Provide guidance on the range of services that can be provided under the "other" category of the regulations.
- Explore the possibility of allowing permanent level-of-care eligibility once a patient is diagnosed with AIDS.
- Develop strategies to encourage more providers to participate in serving AIDS patients.
- Develop strategies to provide housing (including bed and board care) and nonmedical services under the waiver program.

Appendix A

HCFA FORM 372

Annual Report on Home and Community-Based Services Waivers

State _____
Reporting Period _____
Waiver Number _____
Waiver Title _____

Department of Health and Human Services
Health Care Financing Administration
Form Approved OMB No. _____
Page 01.

Level/s of Care in Approved Waiver	SNF (1)	ICF (2)	ICF/MR (3)
I. Annual Number of Institutional Long-Term Care Recipients with Waiver			
A. Institutional LTC recipients			
A.1. ICF/MR services	_____	_____	_____
a. Nonwaiver recipients	_____	_____	_____
b. Waiver recipients	_____	_____	_____
A.2. ICF/all other services	_____	_____	_____
a. Nonwaiver recipients	_____	_____	_____
b. Waiver recipients	_____	_____	_____
A.3. SNF services	_____	_____	_____
a. Nonwaiver recipients	_____	_____	_____
b. Waiver recipients	_____	_____	_____
A.4. Mental health facility SNF/ICF services	_____	_____	_____
a. Nonwaiver recipients	_____	_____	_____
b. Waiver recipients	_____	_____	_____
B.1. Total unduplicated LTC recipients (Actual Factor A value/s)	_____	_____	_____
a. Nonwaiver recipients	_____	_____	_____
b. Waiver recipients	_____	_____	_____
II. Annual Expenditures for Institutional Long-Term Care with Waiver			
A. Total institutional LTC expenditures			
A.1. ICF/MR services expenditures	\$ _____	\$ _____	\$ _____
a. For nonwaiver recipients	\$ _____	\$ _____	\$ _____
b. For waiver recipients	\$ _____	\$ _____	\$ _____
A.2. ICF/all other services expenditures	\$ _____	\$ _____	\$ _____
a. For nonwaiver recipients	\$ _____	\$ _____	\$ _____
b. For waiver recipients	\$ _____	\$ _____	\$ _____
A.3. SNF services expenditures	\$ _____	\$ _____	\$ _____
a. For nonwaiver recipients	\$ _____	\$ _____	\$ _____
b. For waiver recipients	\$ _____	\$ _____	\$ _____
A.4. Mental health facility expenditures	\$ _____	\$ _____	\$ _____
a. For nonwaiver recipients	\$ _____	\$ _____	\$ _____
b. For waiver recipients	\$ _____	\$ _____	\$ _____
B.1. Average per capita LTC services expenditures (Actual Factor B value/s)	\$ _____	\$ _____	\$ _____
a. For nonwaiver recipients	\$ _____	\$ _____	\$ _____
b. For waiver recipients	\$ _____	\$ _____	\$ _____

Annual Report on Home and Community-Based Services Waivers

State _____
Reporting Period _____
Waiver Number _____

Page 02.

Level/s of Care in Approved Waiver SNF (1) ICF (2) ICF/MR (3)

III. Annual Number of Institutional Long-Term Care Recipients
Who Received Acute Care Services

A. Acute care services recipients			
A.1. Inpatient hospital services			
a. Nonwaiver recipients			
b. Waiver recipients			
A.2. Physicians' services			
a. Nonwaiver recipients			
b. Waiver recipients			
A.3. Outpatient hospital/clinic services			
a. Nonwaiver recipients			
b. Waiver recipients			
A.4. Laboratory and X-ray services			
a. Nonwaiver recipients			
b. Waiver recipients			
A.5. Prescribed drugs			
a. Nonwaiver recipients			
b. Waiver recipients			
A.6. All other acute care services			
a. Nonwaiver recipients			
b. Waiver recipients			
B.1. Total unduplicated recipients (Actual Factor A' value/s)			
a. Nonwaiver recipients			
b. Waiver recipients			

IV. Annual Expenditures for Acute Care Services to Institutional
Long-Term Care Recipients

A. Total acute care services expenditures			
A.1. Inpatient hospital services expenditures			
a. For nonwaiver recipients	\$	\$	\$
b. For waiver recipients	\$	\$	\$
A.2. Physicians' services expenditures			
a. For nonwaiver recipients	\$	\$	\$
b. For waiver recipients	\$	\$	\$
A.3. Outpatient hospital/clinic services expenditures			
a. For nonwaiver recipients	\$	\$	\$
b. For waiver recipients	\$	\$	\$
A.4. Laboratory and X-ray services expenditures			
a. For nonwaiver recipients	\$	\$	\$
b. For waiver recipients	\$	\$	\$
A.5. Prescribed drugs expenditures			
a. For nonwaiver recipients	\$	\$	\$
b. For waiver recipients	\$	\$	\$
A.6. All other acute care services expenditures			
a. For nonwaiver recipients	\$	\$	\$
b. For waiver recipients	\$	\$	\$
B.1. Average per capita acute care services expenditures for institutional LTC recipients (Actual Factor B' value/s)	\$	\$	\$
a. For nonwaiver recipients	\$	\$	\$
b. For waiver recipients	\$	\$	\$

Annual Report on Home and Community-Based Services Waivers

State _____
Reporting Period _____
Waiver Number _____

Page 03.

Level/s of Care in Approved Waiver	SNF (1)	ICF (2)	ICF/MR (3)
V. Annual Number of Section 1915(c) Waiver Recipients			
A. HCFA approved Section 1915(c) waiver services recipients (Specify each service as in the approved waiver.)	_____	_____	_____
A.1. _____	_____	_____	_____
A.2. _____	_____	_____	_____
A.3. _____	_____	_____	_____
A.4. _____	_____	_____	_____
A.5. _____	_____	_____	_____
A.6. _____	_____	_____	_____
A.7. _____	_____	_____	_____
A.8. _____	_____	_____	_____
B.1. Total unduplicated Section 1915(c) waiver recipients (Actual Factor C' value/s)	_____	_____	_____
a. Deinstitutionalized waiver recipients	_____	_____	_____
b. Diverted waiver recipients	_____	_____	_____
VI. Annual Section 1915(c) Waiver Expenditures			
A. Total HCFA approved Section 1915(c) waiver services expenditures (Specify each service as in the approved waiver.)	\$ _____	\$ _____	\$ _____
A.1. _____	\$ _____	\$ _____	\$ _____
A.2. _____	\$ _____	\$ _____	\$ _____
A.3. _____	\$ _____	\$ _____	\$ _____
A.4. _____	\$ _____	\$ _____	\$ _____
A.5. _____	\$ _____	\$ _____	\$ _____
A.6. _____	\$ _____	\$ _____	\$ _____
A.7. _____	\$ _____	\$ _____	\$ _____
A.8. _____	\$ _____	\$ _____	\$ _____
B.1. Average per capita Section 1915(c) waiver services expenditures (Actual Factor D' value/s)	\$ _____	\$ _____	\$ _____
a. For deinstitutionalized waiver recipients	\$ _____	\$ _____	\$ _____
b. For diverted waiver recipients	\$ _____	\$ _____	\$ _____

Annual Report on Home and Community-Based Services Waivers

State _____
Reporting Period _____
Waiver Number _____

Page 04.

Level/s of Care in Approved Waiver SNF (1) ICF (2) ICF/MR (3)

VII. Annual Number of Waiver Recipients Who Received Acute Care Services

A. Acute care services recipients	_____	_____	_____
A.1. Inpatient hospital services	_____	_____	_____
A.2. Physicians' services	_____	_____	_____
A.3. Outpatient hospital/clinic services	_____	_____	_____
A.4. Laboratory and X-ray services	_____	_____	_____
A.5. Prescribed drugs	_____	_____	_____
A.6. All other acute care services	_____	_____	_____
B.1. Total unduplicated waiver and acute care recipients (Actual Factor C' value/s)	_____	_____	_____
a. Deinstitutionalized waiver recipients	_____	_____	_____
b. Diverted waiver recipients	_____	_____	_____

VIII. Annual Expenditures for Acute Care Services to Waiver Recipients

A. Total acute care services expenditures	\$ _____	\$ _____	\$ _____
A.1. Inpatient hospital services expenditures	\$ _____	\$ _____	\$ _____
A.2. Physicians' services expenditures	\$ _____	\$ _____	\$ _____
A.3. Outpatient hospital/clinic services expenditures	\$ _____	\$ _____	\$ _____
A.4. Laboratory and X-ray services expenditures	\$ _____	\$ _____	\$ _____
A.5. Prescribed drugs expenditures	\$ _____	\$ _____	\$ _____
A.6. All other acute care services expenditures	\$ _____	\$ _____	\$ _____
B.1. Average per capita expenditures for acute care services to waiver recipients (Actual Factor D' value/s)	\$ _____	\$ _____	\$ _____
a. For deinstitutionalized waiver recipients	\$ _____	\$ _____	\$ _____
b. For diverted waiver recipients	\$ _____	\$ _____	\$ _____

IX. Annual Number of Noninstitutional Long-Term Care Services Recipients

A. Formula Factor H Value _____

X. Annual Average Per Capita Expenditures for Noninstitutional Long-Term Care Services

A. Formula Factor I Value _____

Annual Report on Home and Community-Based Services Waivers

State _____
Reporting Period _____
Waiver Number _____

Page 05.

Level/s of Care in Approved Waiver SNF (1) ICF (2) ICF/MR (3)

XI. Data Not Specifically Related to Formula Factor Values

A.1.	Total days of waivered coverage:	_____	_____	_____
a.	Deinstitutionalized waiver recipients	_____	_____	_____
b.	Diverted waiver recipients	_____	_____	_____
A.2.	Total days of institutional long-term care:	_____	_____	_____
a.	Nonwaiver recipients	_____	_____	_____
b.	Waiver recipients	_____	_____	_____
B.1.	Total unduplicated number of institutionalized individuals offered the waiver services:	_____	_____	_____
B.2.	Total unduplicated number of institutionalized individuals accepting the waiver services:	_____	_____	_____
B.3.	Total unduplicated number of noninstitutionalized individuals offered the waiver services:	_____	_____	_____
B.4.	Total unduplicated number of noninstitutionalized individuals accepting the waiver services:	_____	_____	_____
C.	Waiver recipients entitled based on waiver related eligibility requirements only (42 CFR 435.217, 436.217):	_____	_____	_____

1. Total days of waivered coverage: _____

	Annual unduplicated recipients	Total annual expenditures
2. Institutional long-term care services:	2. _____	\$ _____
3. Acute care services:	3. _____	\$ _____
4. Section 1915(c) waiver services:	4. _____	\$ _____
5. Noninstitutional long-term care services:	5. _____	\$ _____
6. Total unduplicated number of recipients:	6. _____	\$ _____

D. Describe the impact of the waiver on the health and welfare of the recipients. Attach documentation to support the assurance that necessary safeguards were taken to protect the health and welfare of the recipients.

E.1. HCFA approved spending ceiling for the reporting period (Formula Factor values CxD): _____

E.2. Expenditures for waiver year reported on Quarterly Medicaid Statement of Expenditures for the Medical Assistance Program (Form HCFA-64.9, Line 1.R.): _____

Certification:

I, executive officer of the State agency, do certify that the information shown on the Form HCFA-372 is correct to the best of my knowledge and belief.

Signed: _____
Title: _____
Date: _____
Contact Person: _____
Telephone Number: (_____) _____

Appendix B

MECHANISMS USED BY STATE MEDICARE AGENCIES TO IDENTIFY PERSONS WITH HIV

State	Diagnosis Codes	Manual Claims Review	AZT Claims Review	2176 Waiver	Other
AZ					PHPS
AR	X				
CA	X				AIDS Registry
CT	X				
DE		X	X		
DC	X				
FL	X				
HI				X	
IL	X				
IN					Prior Authorization
IA*	X		X		
MD					X
MI*		X			Death Certificate
MN*	X				
MO	X		X		
MT*	X		X		
NE	X				
NV		X			
NH	X				
NJ*				X	
NM*				X	
NC					X
OR*		X			
PA*	X		X		
RI		X	X		
SC*	X				
TX*		X	X		
UT*					MD Notification
WA*	X				
WV			X		
WI		X			

SOURCE: National Governors' Association, Health Programs Center for Policy Research.

*DRGs used in the state.

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